UNDERSTANDING THE APPROPRIATE METHODS OF KNOWLEDGE TRANSLATION FOR PARENTS OF CHILDREN WITH AUTISM SPECTRUM DISORDER (ASD) IN THE CONTEXT OF PAKISTAN

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DECLARATION

This work has not previously been accepted in substance for any degree and is not being concurrently submitted in candidature for any degree.

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ABSTRACT

Early development of service delivery in a large country with many competing demands on resources needs careful consideration. Assessing the setting and needs of the target audience prior to service delivery is important for knowledge-translation initiatives to succeed even in developed countries. This becomes more important in the case of developing countries such as Pakistan where underdeveloped resources, dysfunctional health systems, limited health budget, severe shortage of mental health workforce and limited understanding of neurodevelopmental disabilities among relevant professionals pose plenty of challenges in providing adequate health care services to children with disabilities and their families (Elsabbagh et al. 2012; Malhotra and Vikas, 2005; Sharan, 2008; Samadi, 2011; Tareen et al. 2008; WHO, 2005). In addition, developing best practice principles with limited available resources, when ASD is an emerging field in Pakistan, is a challenge. Assessing the setting and understanding of the needs of parents and professionals becomes vital.

This study aimed to examine the most appropriate methods of knowledge translation for parents of children with ASD in the context of Pakistan. Following the Knowledge-to-Action (KTA) model of Knowledge Translation (KT), the study encompassed several phases. As this was a multiple-staged study for developing best practice principles, different research instruments were used at different stages according to the needs of the study in order to collect necessary data.

To gain insight into the current attitudes and status in Pakistan, two questionnaires, a series of interviews and a focus group with parents of children with ASD living in Pakistan and professionals working with these families were administered at the beginning of the study. This allowed data to be collected on service provision, the satisfaction of parents with the services provided, as well as their needs regarding a potential parent support pack.

Data were also collected regarding the type and level of information that should be provided to parents of children with ASD with reference to the Pakistani context and the best medium for the information to be provided, again with reference to the Pakistani context.

The results of the study indicated that current provision for children who may have ASD and their families living in Pakistan was very limited. There was no provision of staff within mainstream schools for such children, nor was there any respite care for them. The few special schools and therapy units that were available for children with ASD were located in the major cities of the country. Additionally, the process of getting a diagnosis for children with ASD was not well organized in Pakistan. Children were sometimes misdiagnosed and the struggle for parents continued, for up to seven years in some cases, to get a diagnosis that matched the child's symptoms. The results also indicated that currently there was very limited provision for parents to gain information or training for supporting their child with ASD in Pakistan.

Findings suggest that a brief and easily readable Urdu booklet would be an appropriate method of transferring information to parents of children with ASD in the context of Pakistan. The reasons included limited resources, limited understanding of the condition among communities and relevant professionals, problems associated with access and cultural constraints.

On the basis of the results of data collected for the present study, a tailored parent information and guidance pack suitable for the Pakistani context was developed by working with a range of stakeholders. Once the prototype was developed and piloted, two questionnaires were administered to parents of children with ASD living in Pakistan and professionals working with these families to evaluate the information and guidance booklet. Implications for future research and practice are discussed.

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LIST OF ABRIVIATIONS

ABA	Applied behaviour analysis
ADHD	Attention Deficit Hyperactivity Disorder
AFA	Action for Autism
APA	American Psychiatric Association
AS	Asperger's Syndrome
ASAF	The Autism Society, US
ASD	Autism Spectrum Disorder
CCL	Canadian Council on Learning
CDC	Centers for Disease Control and Prevention
CDD	Childhood Disintegrative Disorder
CHSRF	Canadian Health Services Research Foundation
CIHR	Canadian Institutes of Health Research
CP	Cerebral palsy
DCD	Developmental Co-ordination Disorder
DGSE	Directorate General of Special Education
GNP	Gross national product
IRIS	Institute for Remedial Intervention Services
IT	Information Technology
KMS	Knowledge Management and Sharing
KT	Knowledge translation
KTA	Knowledge-to-action
LAMI	Low- and middle income
LEA	Local Education Authority
MMR	Measles, mumps and rubella
MR	Mental retardation
NAS	National Autistic Society
NCDDR	National Center for the Dissemination of Disability Research
NGO	Non-governmental organisations
NHS	National Health Service
NI	Northern Ireland
NICE	National Institute for Health and Clinical Excellence
NIDRR	National Institute on Disability and Rehabilitation Research
NTD	National Trust for the Disabled
NWFP	North West Frontier Province
OCD	Obsessive compulsive disorder
OMRU	Ottawa Model of Research Use
PAMG	Pakistan Autism Meet-up Group

PAPA	Parents and Professionals and Autism
PAR	Participatory Action Research
PARIHS	Promoting Action on Research Implementation in Health Services
PDD	Pervasive Developmental Disorder
PDSA	Plan, do, study, act
PEM	Printed educational materials
R.O.I.	Republic of Ireland
RPC	Research Policy and Cooperation
SDPI	Sustainable Development Policy Institute
SEN	Special Educational Needs
SIGN	Scottish Intercollegiate Guideline Network
SPHERU	Saskatchewan Population Health and Evaluation Research Unit
SPSS	Statistical package for social sciences
SSHRC	Social Sciences and Humanities Research Council of Canada
STEP	Special Talent Exchange Programme
TEACCH	Treatment and Education of Autistic and Communication Handicapped Children
TIBM	Tanzeem Idara Bahali Mustehqeen
ToM	Theory of mind
UAE	United Arab Emirates
UN	United Nations
US	United States
WASP	Western Area Support Project
WCC	Weak central coherence
WHO	World Health Organization

CHAPTER 1: INTRODUCTION TO THE THESIS

1.1 Introduction

This chapter provides the contextual background of the study. The layout of the chapter is as follows:

1.2. A personal and professional journey

1.3. Background to the study

1.4. Research questions

1.5. Outline structure of the dissertation

1.6. Conclusion

1.2 A personal and professional journey

There was both a professional and personal reason for this research study. During my three years of work as a lecturer in education, teaching MA in Education, MEd and BEd students, I found myself close to the disadvantaged students, those who had to strive hard to pass the exams and had trouble competing with brilliant students in the same class. I used to try to find ways to make things easier for them to learn, helping them to build their self-esteem and to cope with their weaknesses.

At that time I realised that I wanted to help those in need, and to make the 'neglected' ones feel that they were also as important and that they had worth. I therefore decided to change my field of work from education to special education. Unfortunately, in Pakistan special education was offered

only in two or three public sector universities and one distance learning university, and was not offered in the public sector university where I used to work.

My desire to help those in need took me out of my city, my university, and even my country. I resigned from the job and applied to a leading public sector University of Pakistan far away from my home town where there was a special education department. Due to my previous credentials I was appointed, but had no experience or degree in Special Educational Needs (SEN).

My quest to serve people with disabilities in the best possible way drove me to learn best practices from experts in a developed country, so I came to Britain with no knowledge or experience in SEN, only with a desire to explore the field of disability in order to help serve the disadvantaged children of my country in a better way.

During my three-month stay in my newly-joined university as a lecturer in SEN I found that services for children with disabilities were not very organised in Pakistan; yet there were some facilities and support services already available for visually- and hearing-impaired people, as well as those with physical disabilities, including cerebral palsy, or learning disabilities, known as mental retardation (MR) in Pakistan. Autism and other specific learning difficulties, on the other hand, were neglected fields with little or no understanding about the conditions among professionals or the community. I

therefore took one module on autism when I started my degree (MA SEN) in the UK.

Discussion with other colleagues (e.g. a teacher of children with autism and learning disabilities who worked in India) about current practices and services for such children and their families led to greater insights in other countries, like India. I wished to explore the circumstances in Pakistan and other developing countries and found that facilities or support provided to children with Autism Spectrum Disorder(ASD) and their families appeared to be very limited, and parents had difficulty in obtaining recognition of, and information about, their child's difficulties. This realisation contributed to my growing interest in the field of ASD.

1.3 Background to the study

'Improving the ability of families to address potentially debilitating mental disorders in the context of the family is a key to humane care' (World Health Organization (WHO, 2005, p.12).

This becomes more evident in the case of ASD, as children exhibit a wide range of difficulties in varying degrees ranging from impairments in communication, socialisation and imagination, to restricted, repetitive and stereotypical behaviours, interests and activities (Aarons and Gittens, 1999; Alba and Bodfish, 2011; DSM-IV, 1994; Frith, 2003; Janzen, 1996). In addition, this neurodevelopmental disorder 'includes a wide variety of other possible developmental delays, intellectual disabilities, medical issues, and

co-morbid psychiatric disorders' (Alba and Bodfish, 2011, p.634; National Institute for Health and Clinical Excellence (NICE, UK, 2012). The world to individuals with ASD, as quoted by the National Autistic Society(NAS), UK (2010), 'is a mass of people, places and events which they struggle to make sense of.' As children with ASD show a range of difficulties and may have trouble expressing their basic needs in a socially acceptable or expected manner, parents are left feeling frustrated at being unable to determine their child's needs and how to make them socially adjustable (The Autism Society, US (ASAF) 2013; Bogdashina, 2005; Nguyen, 2006; Powell and Jordan, 2012).

Research indicates that parents of children with autism experience greater stress than parents of children with intellectual disabilities and Down's Syndrome (Debrowska and Pisula, 2010; Pisula, 2007). Shields (2001) also reported that parents of children with autism have a great need of support in the period following their child's diagnosis. Indeed, the amount of care required by a disabled child appears to impact upon multiple aspects of family functioning (Cavaleri et al. 2010; Davis and Carter, 2008), and it directly or indirectly affects the child and its caregiver (Lennard-Brown, 2006); therefore, the development of effective support services to assist families with children with ASD is of obvious importance (Benson et al. 2008; Janzen, 1996; Wachtel and Carter, 2008).

Bogdashina (2005) made the point that autism contains its own language characteristics and means of learning. Therefore, the parent or the instructor

needs to learn it first before attempting to deal with the child. Charman and Stone (2006) supported these views and said that as parents are the first to teach things to their child, their role is very crucial in managing many symptoms associated with autism. Ingersoll and Gergans (2006) added that parent training offers several important benefits for the child and the family. Solomon et al. (2007) also pointed out that providing information or training to parents can help transfer strategies to the child at home and that parent-child relationships are improved through this process.

When parents are given the skills for handling their children with ASD the children are reported to progress well and their problems appear to be reduced to a certain extent (Cavaleri et al. 2010; Chaabane et al. 2009; Ingersoll and Hambrick, 2011; Ministries of Health and Education, New Zealand, 2008; Moes and Frea, 2002; Rocha et al. 2007). Moreover, as a result of transferring appropriate information and skills to parents, reduced parental stress, improved parental optimism and parent leisure or recreation time was also reported in research (Marshal and Marinda, 2002; Smith et al. 2000; Tonge et al. 2006). In addition to that, if families are provided with relevant and effective information, guidance and training, it is likely to assist families with care and lead to reduced levels of stress, thereby preventing possible family breakdown and the need for long-term, out-of-home care (Higgins et al. 2005). Research further indicates that parent training leads to improved parent-child interaction and relationship (Chandler et al. 2002; Luiselli et al. 2000; Rickards et al. 2009; Solomon et al. 2007). Some of the terms used to describe the process of providing such training to a target

group are knowledge translation, knowledge transfer, research utilization, implementation, dissemination and diffusion (Graham et al. 2006; Lyon, 2010; US National Center for the Dissemination of Disability Research (NCDDR), 2007). Out of these knowledge translation is a newer and comprehensive term (Curran et al. 2011; Davison, 2009; Sudsawad, 2007; NCDDR, 2007; WHO, 2012) (see chapter 3).

In recent years, parent information and training programmes have emerged as an important component in the array of services that have been developed to support families who have a child with autism (Benson et al. 2008; Hall and Graff, 2010). A considerable amount of work has been conducted in the UK, USA and other developed countries in developing and improving parent information, and providing training packages in this area such as booklets, leaflets, DVDs, information on the websites, etc. (see chapters 2 and 6). Additionally, interventions such as the use of the EarlyBird programme, Help, Access, and Treatment and Education of Autistic and Communication Handicapped Children (TEACCH) (Autism NI, 2013; NAS, 2010; Rickards et al. 2009; Shields, 2001) etc. are more examples of such programmes. However, in many developing countries like Pakistan, awareness of autism is in its initial stages, and thus the development of any parental support materials and information or training packages for parents of such children is at an earlier stage (Syed et al. 2007).

The absence of sound data related to child and adolescent mental disorders and available health resources for the conditions in Pakistan (WHO, 2005,

pp.9-15) did not allow any conclusions to be drawn about provision for ASD children and their families within a Pakistani context. However, an understanding was gained regarding the provision for children with ASD and their families in countries with similar economic and cultural backgrounds. Action for Autism (AFA, 2008) and Malhotra and Vikas (2005, p.5) stated that 'though the quality and quantity of research which has been carried out in India is not very good; it is still the best among all the developing countries'.

Research showed a lack of epidemiological studies on autism in Bangladesh, India, Iran, UAE and many other developing countries (Autismi- ja Aspergerliittory, 2013; Chaudhary, 2012; Elsabbagh et al., 2012; Ethirajan, 2011; Samadi and McConkey, 2011; Sharan, 2006; Sharan and Sagar, 2008). AFA (2008, p.14) reported that 'there have as yet been no epidemiological studies of autism conducted in India, or in any comparable region of the world in order to provide a definitive estimate of either prevalence or incidence …. Thus, while there are no studies from India, the numbers are likely to be similar'.

The knowledge and understanding of ASD is limited in many developing countries, even among relevant professionals (AFA, 2008). There appears to be only very limited identification, assessment and diagnosis of ASD and less in the way of educational support. Many children who may have ASD do not receive a diagnosis. Sharan (2008, p.1) stated that in developing countries, 'for most young people, mental health … problems are either unrecognized or inadequately treated'. Samadi (2011, p.1027) added that

‘autism is still so new for the Iranian professionals and service providers. Malhotra and Vikas (2005) stated that a majority of children with autism are not diagnosed or are misdiagnosed due to lack of awareness among the general public and to some extent even among the health professionals. In India, Bangladesh and other developing countries, the cases which get an accurate diagnosis and treatment constitute only a very small proportion of the total number of cases prevalent in the community (Autismi- ja Aspergerliittory, 2013; Malhotra and Vikas. 2005).

In many developing countries there are few allied specialist services for children with ASD and their families. Elsabbagh et al. (2012, p.176) stated that in developing countries ‘very little attention is paid to developmental disabilities at policy and implementation level and as a result budget allocations and human resource deployment is directed away from these programs.’ Autismi- ja Aspergerliittory (2013) reported only 20 schools for disabled children in Bangladesh, whereas AFA (2008, p.24) stated that in many areas of India ‘there are no special schools or facilities for children with any disability, let alone children with autism’. Samadi and McConkey (2011) reported limited availability of services for such children and their families in Iran. The Malaysian Psychiatric Association (2010) indicated that many children with autism do not have access to therapy. The government centres that provide therapy are located largely in urban areas and the waiting list is long, while the programmes carried out by non-governmental organisations (NGOs) are out of reach for most common people due to their high cost. Elsabbagh et al. (2012, p.176) stated that ‘dysfunctional health systems’ of

developing countries ‘contribute further to lack of service delivery’ for such children. ‘Where they exist, access to these facilities is also hindered by lack of effective identification and referral programs’. Sharan and Malhotra (2007, p.18) indicated that ‘geographic and economic barriers further render access to the limited services difficult.’ Samadi (2011, p.1027) added that ‘there is still a long way ahead of the policy makers and service providers to offer satisfactory and sufficient services.’

Although no data were found on the prevalence of ASD in Pakistan or services provided for such children and their families, a high ratio of mental health problems were identified. Tareen et al. (2008, p.804) added ‘this is of considerable concern given that Pakistan, a low-income country, is reported to have the world’s highest rates of mental retardation’. They further quoted 19.1/1000 for serious retardation to 65/1000 for mild retardation.

Syed et al. (2007, p.121) has also discussed that ‘mental illness is one of the major health care concerns, with an estimated 10–16% of the general population suffering from mild to moderate mental health illness, and 1% from severe mental illness’. With such a ratio of mental health problems, Pakistan, with an estimated population of 183 million (Population Census Organization, Pakistan, 2013), 43.2% of whom are under 15 years of age (Mubbashar and Saeed, 2001), requires an organised mental health care system. This, unfortunately, is not the case.

In spite of a high ratio of mental health problems, there is a lack of a broad range of services for this population in Pakistan. Syed et al. (2006) in a study on co-morbidities of ADHD (Attention Deficit Hyperactivity Disorder) in the context of Pakistan highlighted the inadequacy of services for children with special needs. They further stated that the few available services were limited to major urban centres of the country, which comprise only 30% of the whole population. They also indicated that in Pakistan the total number of registered psychiatrists equalled no more than 320, with only two registered child psychiatrists for the whole population and no specialised in-patient child psychiatric units. Lack of sufficient healthcare services for children with mental health problems living in Pakistan has also been indicated by Tareen et al:

> There are less than ten trained child psychiatrists for the whole of Pakistan and none available in the public sector. The need to systematically disseminate expertise in management of child and adolescent neuropsychiatric conditions to front line healthcare staff is self evident, if children and their families are to be able to access the care and support they need (Tareen et al. 2008, p.804).

Syed et al. reported that there were two child psychiatrists in 2006, whereas Tareen et al. reported an increase with less than ten in place in 2008. The difference in numbers may be due to the unavailability of data from any authentic government source or because of the difference in the publishing year. But even if the number were ten, this does not cover the needs of the whole population. Tareen et al. (2008) indicated that according to a report for the United Nations (UN) 2006, approximately 66 million of the population were aged 14 or under in Pakistan. They further indicated (2008) that

according to WHO guidelines, at least two child psychiatrists should work full time for every 60,000 children which, unfortunately, is not the case. In low- and middle income (LAMI) countries 'attention on child and adolescent mental health workforce has been lacking. There is a dearth of sub/super-specialists in child and adolescent mental health …. Moreover, there is a severe shortage of even the general mental health practitioners in most LAMI countries' (Malhotra and Vikas, 2005; Sharan and Malhotra, 2007; Sharan, 2008, p.1). WHO (2005, p.21) also pointed out the issue that the 'child and adolescents psychiatrists are relatively rare outside developed countries and there are very few who are fully trained in the developing countries'. Imran et al. (2009, p.895) reported that 'lack of mental health services for this huge young population poses a significant problem'.

On the other hand, although providing appropriate information, guidance and training to parents of children with autism is considered to be an essential component of the child's welfare (Benson et al. 2008; Drew et al. 2002; Hall and Graff, 2010), parents in developing countries struggle to get the required information. Samadi (2011, p.1027) stated that 'parents in Iran have little opportunity to get information about ASD in any formal way'. Malhotra and Vikas (2005) further indicated that in India and many other developing countries 'parents, who need help, do not know where to go'. 'Parents' feelings of uncertainty and frustrations of not knowing how best to help their child' is also reported for these countries (Samadi, 2011, p.1027). Parents' dependency on updating their information through contact with other parents in clinic waiting rooms has also been identified. The reasons for updating

information through contact with other parents include the ‘limited numbers of published books on ASD’ in regional or national languages, ‘and parental inability, or limited ability, in English language’ that ‘makes web-based information and international books inaccessible sources of information’ (Samadi and McConkey, 2011, p.4). Additionally, the mental health effort in developing countries is based primarily on evidence from developed countries, which have vastly different cultural and socioeconomic contexts (Bharath, 2010; Sharan and Saxena, 2006).

In spite of the fact that cultural adaptation of parent information or support material regarding a country’s ‘family values, parental expectations for their child and the methods of child rearing’ is an important consideration as it ‘facilitate successful parenting within a specific group's culture’ (Samadi, 2011, p.1027; US Department of Health and Human Services, 2008; US National Center for the Dissemination of Disability Research (NCDDR), 1999; Xiong et al. 2006), adaptation and modification of currently existing evidence-based practices from the UK, the USA and other countries has not taken place for the cultural context of many developing countries (Samadi, 2011).

Regardless of its importance, parent education or empowerment has not received attention in developing countries (Malhotra and Vikas, 2005). A few noticeable services provided to parents in these countries include three-month parent training programmes in India, mother and child programme by Action For Autism (AFA, 2008) and China (by ‘Beijing Stars and Rain’, 2010).

Whereas in Iran, a recently developed parent education programme 'Omid' was under trial in 2011 (Samadi, 2011). The inadequacy of services provided for ASD children and their families according to the needs of the target audience in developing countries such as Bangladesh, India, Iran, Malaysia, Pakistan and other countries of the region is evident (AFA, 2008; Autismi- ja Aspergerliitto ry, 2013; Elsabbagh et al. 2012; Ethirajan, 2011; The Malaysian Psychiatric Association, 2010; Malhotra and Vikas, 2005; Samadi and McConkey, 2011; Sharan, 2008; Tareen et al. 2008). Majdzadeh et al. (2008, p.270) discuss that 'the importance of using research in health care decision making at the individual and organisational levels is increasingly recognized' in developing countries as well, but these countries 'face challenges' to material development or its application due to 'their limited resources'.

On the other hand, the facilities or support provided to parents of children with developmental disabilities in Pakistan is fairly limited and generally facilitated by NGOs (Syed et al. 2007) usually formed and run by parents of children with disabilities. Imran et al. (2009, p.899) indicated 'the absence of dedicated child and adolescent mental health services in Pakistan'. Tareen et al. (2008) reported little availability of any behaviour or psychosocial treatments, or parent information and guidance materials for children with mental health problems living in Pakistan. They also emphasized that, 'there is the need to tailor evidence-based interventions for these conditions so that they are understandable and easily integrated into existing systems of care.' (2008, p.804) The lack of available data (e.g. any completed or published

research) regarding services provided for the parents further emphasizes the need to explore the situation as it exists in Pakistan to identify the gaps, and to build a system of care as needed.

Being a member of the Pakistan Autism Meet-up Group (which was a platform formed by parents of children with ASD to create awareness about autism and to provide support to parents), and from the discussions on the forum, the problems and difficulties faced by parents in obtaining information about the appropriate way of handling their children with ASD became apparent. Therefore, the present study focused on examining the appropriate methods of knowledge translation for parents of children with ASD in the context of Pakistan.

1.4 Research questions

The aim of the study was to examine: ‘what is the most appropriate method of knowledge translation for parents of children with ASD in the context of Pakistan?’

In order to answer this question, a series of sub-questions were asked:

1. What is the current provision in Pakistan for children who may have ASD and for their parents?
2. What are the current approaches to supporting parents of children with ASD in Pakistan?
3. What methods are being used internationally for knowledge translation for parents of children with ASD?

4. What is the most appropriate method of knowledge translation for parents of children with ASD in the context of Pakistan?

The study followed the approach of knowledge translation, which not only focuses on exploring a situation, but is also based on certain actions to address the identified problem. Therefore, the answers to the asked questions led to the required action or potential solution. The questions asked here formed only one part of the study, and do not represent the whole project. Additionally, the study encompassed several phases where the actions as well as research questions at each stage depended on the results of the preceding stage. Thus, the research questions are presented in chapter 4, woven into the stages of the study for the purpose of clarity and understanding.

1.5 Outline structure of the dissertation

To understand the subject of the study more clearly, a literary review was carried out which is presented in chapter 2 of the dissertation. It contains a literary review on autism, its characteristics, causes, the ways it affects the child and its family, the needs of parents to cope with the challenges associated with parenting such children, approaches to empowering or providing information to parents, services provided for children with autism and their families in developing countries, and an overview on the health care system in Pakistan.

The Research Methodology has been divided into two separate chapters, 3 and 4.

Chapter 3 of the dissertation contains the literary review on the research design and justification for the choice of that method.

Chapter 4 provides details on how the present study was developed. It covers the stages and phases employed with their justification, combined with the description of data collection. It also provides details on the research instruments used in the study, together with sampling procedures, validity and reliability, and ethical considerations.

Chapter 5 contains the results of questionnaires and interviews with parents of children with ASD living in Pakistan and professionals working with these families to establish their views on an appropriate method for transferring information to such parents in the context of Pakistan. It covers data on the existing provision for children with ASD and their families, the satisfaction of parents with the services provided, and their needs regarding any parent support pack. It also presents data on questions such as what information should be provided to parents of children with ASD and in which way it should be provided (content and method appropriate to the Pakistani context).

Chapter 6 describes the process of developing a tailored parent information and guidance pack suitable for the Pakistani context based on the results of

data collected for the present study. It contains a literary review of the development of parent information materials. A more general review of such approaches is presented in chapter 2, but as it was a multiple-stage study, further insight into certain topics was required as the work progressed. In addition, it presents the results of a thematic analysis of parent materials and the process of developing material adopted in the present study. In short, it describes the step-by-step process of identifying and collecting useful, relevant information; filtering, blending, modifying and reproducing information collected from a variety of sources to develop a relevant, focused and useful parent information and guidance pack.

Chapter 7 presents the results of questionnaires completed by parents of children with ASD living in Pakistan and professionals working with these families to evaluate the parent information and guidance booklet developed as a result of this study.

Chapter 8, the final chapter, presents the conclusions and implications of the study.

1.6 Conclusion

This introductory chapter has presented the background to the research and its context in the Pakistan setting. Briefly reflecting on current services, it describes the importance and relevance of this work. It has also provided an outline of the dissertation.

CHAPTER 2: LITERARY REVIEW

2.1. Introduction

This chapter provides a review of literature pertaining to this study. Beginning with an overview of autism spectrum disorder (ASD) and its aetiology, it will present the problems associated with the condition as well as the challenges in parenting children with ASD. Potential solutions to these problems will be considered in the review by stating the approaches to empowering or providing information to parents and their pros and cons. Finally, it will describe the provisions for such children and their families in the developing countries as well as in Pakistan.

It is important to state at the outset that research completed on the provisions for ASD children and their families in Pakistan is very scarce. It was hard to find authentic information on provisions for ASDs when data was not even available from government sources on the overall healthcare system (WHO, 2005). Limited availability of published research or authentic data on the issue was identified for other developing countries as well (Elsabbagh et al. 2012; Sharan and Saxena, 2006). WHO (2004) stated that 'over 85% of the world's population lives in the 153 countries categorized as low- and middle-income, according to World Bank criteria.' Yet 'at present, only a minute proportion of research published in widely accessible mental health and psychiatric journals is from or about these countries', therefore, only limited references can be quoted on this issue in the literary review.

2.2. An overview of autism[1]

The word ‘autism’ is a combination of two Greek words, ‘aut’ meaning ‘self’ and ‘ism’ meaning ‘orientation or state’. Thus the word autism was applied to children who appear to remain absorbed in themselves with little or no interest in others (Dodd, 2005, p.1). The condition was first described by Leo Kanner in 1943, who identified a group of children displaying similar characteristics related to social isolation, difficulties with imagination, impairment in communication, repetitive and stereotyped play (Aarons and Gittens, 1999; Klin, 2006; Tager-Flusberg, 2010; Zwaigenbaum et al. 2007). He named it ‘early infantile autism’ (Quill, 2000). A year later, Hans Asperger published a paper in German Literature indicating a condition similar to the one found by Kanner (Aarons and Gittens, 1999; Klin et al. 2005). Autism was considered a disability by The American Psychiatric Association (APA) in 1980, and was included in a Diagnostic and Statistical Manual of Mental Disorders – 3rd Edition (DSM-III) (Bernier and Gerdts, 2010; Zager, 2005).

Intensive work in the field of research has revealed the complexity of the disorder. It is now known as a spectrum disorder (Happe, 1994; State of Michigan, 2012) because it affects each individual differently and to varying degrees (Ministry of Health, New Zealand, 2008). The characteristics of autism vary from individual to individual (NICE UK, 2012), and each

[1]The terms Autism Spectrum Disorder (ASD) or Autism used in the dissertation refer to an autistic disorder defined by DSM-IV or ASD by DSM-V, as these terms are sometimes used interchangeably (Filipek et al. 1999, p.440; NICE, 2012, pp.4–5) not only in Pakistan but also worldwide to refer to an autistic disorder or ASD (Bernier and Gerdts, 2010, p.13; PAPA, Autism NI).

individual's experiences are unique (Jordan, 1999). For example, some people with autism may have no verbal language at all (Bernier and Gerdts, 2010), some may have fairly limited speech, while others may have apparently good language skills with some difficulty in higher functioning (Charman, and Stone, 2006). It has also 'been described as a triad of impairments involving delay and deviance in social and communicative development, along with restricted interests and repetitive behaviours. Certain sensory, motor and cognitive characteristics are also associated with autism' (Prior and Roberts, 2012, p.1).

Autism has also been considered a 'hidden disability' as symptoms are not easily recognised compared to those of a physical kind (Lennard-Brown, 2003; NAS, UK, 2010). Apparently, children with autism may look like typically developing children (Aarons and Gittens, 1999) as autism is not a physical disability, although some children with autism have motor difficulties as well (Campos et al. 2009): the difficulties that are necessary for a diagnosis of ASD include impairments to communication, social interaction and imagination. Janzen (1996, p.5) indicated that it is a neurobiological disorder of development that causes discrepancies or differences in the way information is processed. This information-processing difference affects the ability to understand and use language to interact and communicate with people; understand and relate in typical ways to people, events and objects in the environment; to understand and respond to sensory stimuli such as pain, hearing taste, etc., to learn and think in the same way as typically developing children.

People with ASD show a range of difficulties which make it more complicated for parents and professionals to treat the individual with one particular intervention. Matson et al. (2010) and the National Autistic Society (NAS, 2012) highlight the fact that symptoms of autism are severe, lifelong, and can be further complicated by co-occurring conditions including various forms of psychopathology. Alba and Bodfish (2011, p.634) indicate that autism 'includes a wide variety of other possible developmental delays, intellectual disabilities, medical issues, and co-morbid psychiatric disorders'. Bernier and Gerdts (2010, p.15) further added that 'associated symptoms may include sleep disturbances (difficulty falling and staying asleep), gastrointestinal problems (e.g. constipation and abdominal pain), and neurological problems, including an increased risk of seizures'.

The individual with autism finds it difficult to understand the world around them and to make sense of it (Frith, 2003). According to NAS (2010) the world to individuals with autism 'is a mass of people, places and events which they struggle to make sense of, and which can cause them considerable anxiety'. As individuals with autism cannot understand social rules, communication patterns and ways of interacting, their families also suffer considerable anxiety in an attempt to make them socially adjustable (ASAF, 2013; Bogdashina, 2005; Nguyen, 2006; Powell and Jordan, 2012).

2.2.1. Terms used for autism and related disorders

The term used for autism in DSM-IV is 'autistic disorder', which comes under the category of ASD in the manual (APA, 1994; APA, 2010; Autism Speaks Inc, 2013; Janzen, 1996). The umbrella term for the condition originated by WHO is Pervasive Developmental Disorder (PDD) as presented in their tenth revision of the International Statistical Classification of Diseases and Related Health Problems (ICD-10) in 1993. The acronyms PDD or ASD in DSM-IV and ICD-10 are not a specific diagnosis, but umbrella terms under which the specific diagnoses are defined (Autism Society, US, 2010).

There are a number of disorders which are considered in the same category as autism. Some of these are Asperger's Disorder, Rett's Disorder, Childhood Disintegrative Disorder (CDD) and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS) as presented in DSM-IV. The ICD-10 classification includes Childhood Autism, Atypical Autism, Asperger's Syndrome (AS), Rett's Syndrome, Other Childhood Disintegrative Disorder and Pervasive Developmental Disorder Unspecified.

Combining the disabilities into one group was justified by WHO (ICD-10, clinical description and diagnostic guidelines. p.21): 'These disorders have been described in one group because evidence suggests that this may have considerable practical utility.' Though each term described under these categories may account for a different set of symptoms associated with it, the umbrella terms have been designed very carefully by WHO and the American Psychiatric Association (APA) to refer to a group of individuals who

share some characteristics in common. For example, children with ASD or PDD may find it hard to understand the perspective of others, or the unpredictability of the world around them. Frith (2003) also indicated that diagnostic labels are used to indicate commonalities among individuals. The key defining symptom of autism that differentiates it from other syndromes and/or conditions is substantial impairment in social interaction.

Specificity of autism is considered a complicated phenomenon. The Autism Society, US (ASAF, 2010) indicated that although autism is defined by a certain set of behaviours, children and adults with autism can exhibit any combination of these behaviours in any degree of severity. Two children, both with the same diagnosis, can act completely different from one another and have varying capabilities. The problem of specificity of autism was also reflected by Janzen (1996, p.5) that some children with ASD may suffer from fears, obsessions, and other forms of deficit where as others may not. Not all children designated as having ASD need to show all the signs or patterns of deficit. In addition, some typically developing children may also show some of these behaviours which leads to the problem of specificity. On the other hand, the APA (2010) reported that 'differentiation of autism spectrum disorder from typical development and other "non-spectrum" disorders is done reliably and with validity; while distinctions among disorders have been found to be inconsistent over time, variable across sites and often associated with severity, language level or intelligence rather than features of the disorder'.

DSM-V has merged all the above sub-disorders into one category named Autism Spectrum Disorder (APA, 2010, 2013; Borden, 2011; Kaufmann, 2012). There is one diagnostic criteria for Autistic Disorder, Asperger's Disorder and Pervasive Developmental Disorder Not Otherwise Specified (APA, 2010, 2013; Bernier and Gerdts, 2010; Kurita, 2011). APA (2010) stated that the need for revision was felt for specificity and simplification of the disorder. As the disorders discussed above have a common set of behaviours and are in the same category, combining them can make it easier for the clinicians, and other practitioners to work with the individuals with better understanding of the conditions and interventions.

A justification for revising the diagnostic criteria for autism states that:

> Because autism is defined by a common set of behaviors, it is best represented as a single diagnostic category that is adapted to the individual's clinical presentation by inclusion of clinical specifiers (e.g., severity, verbal abilities and others) and associated features (e.g., known genetic disorders, epilepsy, intellectual disability and others.) A single spectrum disorder is a better reflection of the state of knowledge about pathology and clinical presentation (APA, 2010).

DSM-V has been published recently. As indicated by APA (2011; 2012; 2013), the new name for the category is autism spectrum disorder. APA (2013, p.1) indicated that 'a single umbrella disorder will improve the diagnosis of ASD without limiting the sensitivity of the criteria, or substantially changing the number of children being diagnosed'. CDC (2014, p.1) reports, 'A diagnosis of ASD now includes several conditions that used to be diagnosed separately: autistic disorder, pervasive developmental disorder

not otherwise specified (PDD-NOS), and Asperger syndrome. These conditions are now all called autism spectrum disorder'.

2.2.2. Co-occurring disorders with autism

Gilger and Kaplan (2001) were of the view that the term 'co-morbid' should not be used for disorders which have a common cause, but should be reserved for those which co-occur. Kirby (2005) on the other hand suggested alternative terms including 'co-occurrence', 'associated', 'co-existing' and 'overlap'. Therefore, the disorders which have the common cause or features of autism were discussed under the preceding heading (2.2.1), whereas the disorders which co-occur with autism are discussed here.

There are many conditions that co-occur with autism spectrum disorders, such as 'dyslexia, dyspraxia, attention deficit hyperactivity disorder (ADHD) and learning disabilities (Ghaziuddin et al., 2010; NAS, 2012; NICE, 2012). Dyspraxia is internationally known as developmental co-ordination disorder (Kirby and Sugden, 2007; NHS UK, 2012), and often co-occurs with ASD (Hill, 2005; Kaplan et al. 1997; NHS UK, 2007; Sugden, 2006). Parents and Professionals and Autism (PAPA), a Northern Ireland autism charity, indicated that 'around 50% of people with ASD will have an accompanying learning disability'. Simonoff et al. (2008, p.921) and Witwer and Lecavalier (2010) added 'psychiatric disorders are common and frequently multiple in children with autism spectrum disorders'. Other co-occurring conditions include Fragile X syndrome, epilepsy, bipolar disorder, obsessive compulsive disorder (OCD) and anxiety disorders (Garcia et al. 2008; Leyfer et al. 2006;

Simonoff et al. 2008; Van Steensel et al. 2013). Intellectual disability and slow motor development are also commonly observed (Campos et al. 2009; Kuhn and Matson, 2002).

2.2.3. Prevalence of autism

ASD is reported to be more prevalent in children 'than cancer, Diabetes, Spina Bifida, and Downs Syndrome' (Filipek et al. 1999, p.440; Texas Statewide Leadership for Autism Training, 2009). It is the fastest-growing developmental disability with 1.15% growth rate (ASAF, 2012). Autism Speaks (2012) and Lennard-Brown (2003) argue that careful research shows that this increase is partly explained by improved diagnosis and awareness.

Autism occurs in all racial, ethnic, and socioeconomic groups (CDC, US, 2014) and is more likely to occur in boys than in girls (ASAF, 2014). The sex ratio of male to female with autism is 4:1 (Bernier and Gerdts, 2010). Its prevalence is estimated to be somewhere between 1 in every 100 (NAS, UK, 2012; PAPA, NI; Simonoff et al. 2008), and 1 in every 88 children (Autism Speaks, US, 2012; CDC, US, 2012), and has been cited in boys as present between 1 in 70 (ASAF, 2012) and 1 in 54 (Autism Speaks, US, 2012). Elsabbagh et al. (2012), in a report on the global prevalence of autism to WHO, based on a systematic review of all available evidence (studies conducted between 2000 and 2011 in different areas and by different researchers), stated that the prevalence of all forms of autism combined is estimated to be 1 in 160 individuals. But, due to several differences across studies, the figure does not strictly represent a worldwide estimate. Instead,

this is an average figure and a general reflection of the current state of evidence. Elsabbagh et al. (2012) and Zaroff and Uhm (2012) argued that available evidence suggests that methodological factors are largely responsible for the differences in ASD prevalence across studies.

2.2.4. Causes of autism

Although there is evidence to suggest that autism is a multi-factorial disorder, an adequate understanding of the genetic and non-genetic causes has yet to be achieved (Autism Speaks, US, 2012; Rutter, 2005; State of Michigan, 2012). Aetiology of autism is still an unsolved phenomenon (Lennard-Brown, 2003). 'No specific cause has yet been identified' (CDC, US, 2014; Prior and Roberts, 2012, p.1). Researchers, however, are trying hard to discover the actual causes of autism.

2.2.4.1. Brain structure

Research seems to provide good evidence that autism is a disorder that is related to a problem in the growth or development of the brain (Klin, 2006; Koenig et al. 2001). Aarons and Gittens (1999) and Lennard-Brown (2003) indicated that the causes of autism are not completely understood, but recent research into brain function has shown that autistic behaviour is directly linked to changes in brain structure.

Lennard-Brown (2003) added that 'changes in several areas of the brain, including the limbic system and frontal lobes' are linked with autism. Hippocampus, amygdala, Purkinje cells in the cerebellum and other areas of

the brain have been discussed also as being involved (Fatemi et al. 2002; Schultz, 2005).

2.2.4.2. Genetics and autism

Research is being carried out to identify the relationship between genes and autism, but there is still great debate and argument about the real cause of it (Freitag, 2007; Freitag et al. 2010). Chew (2006) reported that autism has occured through imbalances in brain development involving the enhanced effects of paternally expressed imprinted gene, deficits of effects from maternally expressed genes or both. A number of studies have been carried out on genes, chromosomes, neurologins, etc. to find out their relationship with autism, and it has been reported that autism has a genetic cause (Blasi et al. 2006; Feinstein and Reiss, 1998; Hessl et al. 2008; Lauritsen, 2007; Libbey et al. 2008; Van Rifn et al. 2008). 'Although there is growing evidence that autism may be inherited to a significant degree' (Prior and Roberts, 2012, p.1; State of Michigan, 2012), the part of the the brain which is affected has not been identified, nor which gene is the exact cause of autism.

Szatmari (2003) and CDC (2012) added that many factors may be involved in causing autism in children such as environment, biologic and genetic factors. Janzen (1996, p.6) indicated a similar point that 'autism is a syndrome, or condition, with many possible causes. Anything that makes the central nervous system develop abnormally can cause autism'. Children who have a sibling or parent with autism are also reported to be at a higher risk of having autism (CDC, US, 2012; Zwaigenbaum et al. 2007).

2.2.4.3. Gene-environmental interactions

In theory there are very few who would argue against the role of genetics in autism. Yet emphasis on genetic causes at the expense of ignoring other contributing factors may not be welcomed by many researchers. Certain factors that may also play a crucial role in causing this disorder are identified by different studies. Action for Autism, India (2008) and Autism Speaks, US (2009) indicated that although we know that genetics is an important factor, genetics alone may not account for all cases of autism. The increase in the reported number of autism cases has generated extreme concern over the potential involvement of toxins as well as infectious agents in our environment. Fatemi et al. (2003) argued that certain genes may make someone more likely to develop autism: but for autism to occur, these genes may have to be switched on by something in the environment. Lennard-Brown (2003) also indicated that recent research suggests that autism may result when a child with a genetic susceptibility is exposed to one or more of a number of environmental insults resulting in a series of dysfunctional interactions between genes and nutrients.

2.2.4.4. Contentious ideas

Research indicates that the critical period for developing autism occurs before birth, however, concerns about vaccines and infections have led researchers to consider risk factors before and after birth (CDC, US, 2012).

Action for Autism, India (2008, p.25) stated that ‘genetic factors do not explain all cases of autism, and there are a host of other hypothesized

causes'. These include risk factors such as maternal antibodies (Leitch, 2008), maternal age (Baxter et al. 2007), medical conditions such as Down's syndrome, Fragile X syndrome (CDC, 2012) and problems related to the birth of a child (Brimacombe et al. 2007). Additionally, a forceful argument is made by some parents of autistic children and some researchers that the measles, mumps and rubella (MMR) vaccine may be a cause of autism (Lennard-Brown, 2003; Schultz et al. 2008), however, extensive evidence has shown no link to these vaccines in causing autism (Autism Speaks, US, 2012; Lennard-Brown, 2003; National Autistic Society, UK, 2010; Szatmari, 2003). Godlee et al. (2011) and the Ministries of Health and Education, New Zealand (2008, p.13) further stated that 'there is no scientific evidence to support the view that this vaccine has a role in causing ASD'. Roehr (2013, p.1) reported that 'no association between vaccination exposure and the development of autism spectrum disorder was found in a new study'. Action for Autism (AFA, 2008, pp.25–26) stated that 'of all topics related to autism, the MMR–autism controversy in particular has been fuelled by media attention', however, the evidence does not conclusively show a causative association between any of the above said factors and autism.

2.2.5. Diagnosis of autism

Diagnosing autism can be difficult since there is no medical test, such as a blood test, to diagnose the disorder (CDC, US, 2014). Diagnosis usually depends on parental reports, and professionals' observation of a child's behaviour and developmental history, which is sometimes combined with certain tests for hearing, vision etc. (ASAF, 2012). A growing body of

research suggests that autism can be accurately diagnosed by two years of age (Bishop et al. 2008; Charman and Baird, 2002) and the diagnosis given then is accurate as well as stable over time (Bernier and Gerdts, 2010; Eaves and Ho, 2004; Lord et al. 2006), but predictive validity of assessment at three years is found to be greater than at age two (Charman et al., 2005; Daalen et al. 2009).

Autism is sometimes identified at a very early age, but it may take years to get a proper diagnosis. Dodd (2005) presented potential reasons for a late diagnosis and suggested that though assessment tools are available to identify at an early age, children with high intelligence may be missed. Janzen (1996) also supported the views presented above that in many cases, the condition that results in autism is likely to be present at birth, but the indicators of autism are generally not obvious until there is a failure to develop some of the early social and communication skills. Paediatricians can sometimes detect the indicators as early as twelve to eighteen months of age; but some more capable and quite verbal young children show few or only mild characteristics until they are eight to ten years of age.

Diagnosis of autism is usually based upon the DSM-IV/V or ICD-10. These are considered the main diagnostic reference of mental health professionals (ASAF, 2010; Bernier and Gerdts, 2010; Zager, 2005). See Appendices A and B for the diagnostic criteria of DSM-IV and ICD-10. Unfortunately, the diagnostic criteria of DSM-V was not included in the appendix as it was unavailable on APA's websites or in University of South Wales' library due to

its recent publication (see 2.2.1). Buying it for the dissertation was not considered due to the researcher's limited resources and the focus of the study on providing information to parents.

2.3. Presenting symptoms of autism

Powell and Jorden (2012) indicated that the reasons behind 'autistic ways of behaving' should be considered first, whereas the guidance about ways of responding to the issues should be provided to parents and teachers on the basis of clear understanding of the conditions associated with autism. Autism is a complex disorder that makes it very complicated for parents and care givers to understand a child's behaviour or needs (Happe, 2002; Lennard-Brown, 2003; NAS, 2012; Rao et al. 2008). An important step in resolving the problem is to gain a clear understanding of the wide range of difficulties associated with autism (Nguyen, 2006), therefore, the conditions associated with autism, the possible reasons behind these problems and the way they affect the child are briefly presented in this section.

2.3.1. Difficulty with communication and its impact

Difficulty with communication is a core deficit for children with autism, where all children suffer from some kind of difficulty in communication (NICE, 2012; Rao et al. 2008). As autism is a spectrum disorder that affects each individual differently and to a varying degree, children on the spectrum exhibit a wide range of problems within each area of impairment. Some children with autism have no verbal speech at all, while, some may have fairly good language, but may have a literal understanding of the words.

Prizant and Wetherby (2005) indicated that around forty percent of children with autism are non-verbal, whereas the remaining majority may have echolalia; they may remember and repeat words or phrases without understanding the meaning of them. Leyfer et al. (2006. p.850) supported this by saying that 'half of the individuals with autism are functionally nonverbal', whereas the remaining half with 'adequate language' suffer from 'a variety of other types of communication impairment.'

Dodd (2005, p.57) indicated that children with autism 'have difficulty understanding and using all forms of communication including speech, sign language, body language, tone of voice, gestures and vocalization.' Prizant and Wetherby (2005) and Noens and Onnes (2004) added that these children have a problem understanding and using body language such as gestures and facial expression. While talking their faces may look blank with no facial expression, making it hard for others to understand what they actually mean. Charman and Stone (2006) argued that children with autism tend not to use non-verbal communication firstly, because they are unaware of how to use it, secondly, they have difficulty understanding the meaning of these body expressions, and finally, they do not use it as they lack the desire to communicate. Aarons and Gittens (1999) and Bogdashina (2005) added that language used by children with autism is often irrelevant to the social context and does not form a part of a social exchange. They may talk a great deal, regardless of the listener's response, and have difficulty in engaging in reciprocal conversation (Deudney and Tucker, 2009; Gray, 2006).

Problems with communication may impact so badly on the child's life that the child has difficulty in communicating even his basic needs or wants. When the needs are not communicated to caregivers they may not be met, resulting in behaviour problems in children with autism and frustration on the part of parent or care giver as well as the child (NAS, 2010). Noens and Onnes (2004) stated that most of the challenging behaviour is exhibited because of communication difficulties. It has been found that communication difficulties may be directly related to and cause challenging behaviours (Chiang, 2008). Chiang and Carter (2008) added that children with autism also have problems in spontaneity of communication. Most of the time, children depend on the cues or prompting for the initiation of the conversation. They may also experience difficulty perceiving the intention behind changes in voice intonation, and the change of pitch or pause in a sentence (Powell and Jorden, 2012). The problem of initiating a conversation or participating in one makes them appear aloof and as a consequence socially unaccepted.

2.3.2. Difficulty with socialisation and its impact

Socialisation is another core area of deficit for children with autism (NICE, 2012). They have marked impairments in socializing with others (Schultz, 2005). Tager-Flusberg (2010) and Gracia et al. (2007) added that children with autism lack the skills of peer interaction at an early age. They find it hard to make new friends, or to maintain good relationships with already existing friends. Their social skills are quite poor and may be different from those of typically developing children. The Ministries of Health and Education, New

Zealand (2008, p.12) indicated that ‘ASD is sometimes regarded as a ‘hidden’ disability that affects every aspect of a person’s day-to-day life, including social inclusion’.

Rao et al. (2008) indicated that ASD is a complex neurological disorder that leads to deficits in a child's ability to play, develop social skills, and relate to others. The children on the spectrum exhibit a range of difficulties regarding socialisation. Some individuals prefer to be on their own and like their own company; some may like to make friends, but do not have the skills to do so. Some children may succeed in making friends but may be ‘odd’ compared to peers so that they may prefer to have friends older than them rather than of their own age. Chiang and Carter (2008) added that children with autism lack the spontaneity or initiation of social interaction. Charman and Stone (2006) indicated that joint attention and social reciprocity are one of the major problems for children with autism. They have problems in sharing their feelings, needs and interests (Deudney and Tucker, 2009; Gray, 2006; Hannah, 2001).

Individuals with autism also suffer from problems with establishing relationships (Prizant and Wetherby, 2005), for example, in school, within their family, etc. If not addressed in time, this impairment of socialisation can have a very lasting effect on these children. They may not be able to enjoy a typical childhood, youth or adulthood like other typically developing children.

2.3.3. Difficulty with imagination and related theories

Imagination and perception is another area of difficulty for individuals with autism and may affect a child in many different ways (Howlin, 2005; Klin, 2006). For example, they may find it hard to understand what another person means by an action, or what the future will hold, and what would happen in the near or far future, etc. (O'Brien and Pearson, 2004; Schultz, 2005; Tager-Flusberg, 2010). The problem of not perceiving the intentions of others may result in misunderstandings, whereas the child's inability to perceive the future may cause anxiety due to any sudden change (NAS, 2011).

Certain theories have been presented focusing on the particular deficits that may be responsible for many of the symptoms exhibited by children with autism. Among these, the widely discussed theories include 'theory of mind', 'central coherence', and 'executive functioning'. Bolte et al. (2007, p.1493) explained that 'a lack of theory of mind is the most important prominent cognitive model for failure in social and communicative reciprocity, while executive dysfunction and weak central coherence (WCC) serve to explain the non-social aspect of the disorder'. As the mind-blindness theory of autism could not explain the non-social features (the narrow interests, need for sameness and attention to detail), the 'empathizing–systemizing (E-S)' theory developed by the same psychologist serves to explain both the social and non-social features (Baron-Cohen, 2009; Nettle, 2007). It 'explains the social and communication difficulties in autism and Asperger syndrome by reference to delays and deficits in empathy, while explaining the areas of

strength by reference to intact or even superior skill in systemizing' (Baron-Cohen, 2002; Baron-Cohen, 2009).

Although, several theories have been presented in this regard, only a few are briefly presented here considering that the focus of the study is on parent training.

Literal and fragmented perception

Chiang and Carter (2008) stated that children with autism suffer from perceptual difficulties. Bogdashina (2005) indicated that the perception of children with autism is quite literal and fragmented. They appear to perceive things as they are, without understanding or interpretation. The way individuals with autism perceive things was explained by an individual with autism. Bogdashina (2003, p.45) quoted Blackburn (1999, p.10): 'Most things I take at face value without judging or interpreting them. I look at them in a concrete, literal, and very individual way. I do not normally integrate things or see them as connected unless I actively look for a connection.'

An individual with autism explained fragmented perception as:

> Fragmented perception means I might have difficulty dealing with people – because a person may appear as a lot of unconnected parts, each one of which is unpredictable. The strategy to cope with the problem is to avoid people and never look at them. It does not mean I can't see an entire person, but I may be unable to process the meaning of an entire person and process them bit by bit instead. As a result the mental image of a collection of bits is often meaningless and often frightening (Daly et al. 2007, p.11).

Gestalt perception

Individuals with autism also suffer from the problem of filtering information. They often find it hard to discriminate between relevant and irrelevant information, or ‘distinguish between foreground and background information’ (Bogdashina, 2003, p.46). Gestalt perception was explained as:

> Someone with Gestalt perception will have difficulty if one slight detail is changed. For example, if a picture on the wall is not straight or a piece of furniture has been moved this changes the gestalt of the whole scene and the environment will feel unfamiliar. This can cause fear, stress and frustration (Daly et al. 2007, p.10).

WCC is one of the major theories in this regard (Bogdashina, 2003). Bolte et al. (2007, p.1493) explained that the WCC theory according to Frith and Happe (1994) ‘postulates that individuals with autism prefer a cognitive style characterized by piecemeal or local processing, rather than context-driven or global processing’. Conversely, Ozonoff et al. (1994) explained in their study results that individuals with autism did not demonstrate trouble in processing global features of stimuli. They argued on the base of their study results that an individual with autism might have no difficulty in visually perceiving the whole picture. Bogdashina (2003, p.47) added that children with autism may ‘focus on details at the expense of seeing the big picture, but they do it at a conceptual, rather than a perceptual, level’. Mottron et al. (2003) stated that individuals with autism can process local and global visual stimuli (parts and wholes) just like typically developing children, but they have a problem assigning importance to specific stimuli and putting them into a processing hierarchy.

Theory of mind (ToM)

Individuals with ASD have problems in relation to their theory of mind (Hale and Fusberg, 2005; Saxe and Baron-Cohen, 2007). Theory of mind has been related to the child's ability for thinking and perceiving (Baron-Cohen, 2001). Sprung (2010, p.204) explains, 'ToM is awareness of own and other people's mental states, such as beliefs, desires, intentions, and emotions. These mental states are revealed largely through conversation and are the foundation of social understanding'. With an impaired theory of mind, children with autism face plenty of challenges (Howlin et al. 1999; Howlin, 2005). The impairment of ToM has also been linked to social aloofness (Tager-Flusberg, 2007). Sprung (2010, p.211) added that the 'ToM deficits can also limit children's awareness of (and ability to report on) cognitive symptoms and may even limit awareness of illness in general'.

Another form of perceptual difficulty is considering the perspective of others (Saxe and Baron-Cohen, 2007). Individuals with autism lack the ability to read another person's mind (Baron-Cohen et al. 2009) and to consider that others may have a different perspective than that of his own (Hannah, 2001). They find it hard to think that the other person's interest, experiences and vision can be different from their own. Likewise, they have problem understanding that if they have watched a movie or have seen an incident, others would not have seen it. When describing an incident or talking about a movie, full context should normally be used to make it easy for others to understand but as children with autism lack this ability, they may describe fragmented bits of an incident and may not convey any message with

complete meaning. The problems of imagination and perception significantly affect the child's communication and socialisation (Rao et al. 2008).

On the other hand, some children with autism may talk at great length about their interest (Bogdashina, 2005, p.192) without considering the interest of others. They find it hard to understand that others may not share the same level of intensity in the object or issue or may not be interested in their area of interest at all. This adversely affects their ability to maintain a positive relationship with anyone. Sprung (2010, p.205) added that failure to consider the mental state of others has been linked to social exclusion and social dysfunction.

2.3.4. Sensory difficulties and their impact

Individuals with autism often have sensory sensitivities (Cumin et al. 2000; Gray, 2006; Hannah, 2001; NAS, 2012). Janzen (1996, p.5) said that some individuals with autism 'may suffer from hypersensitivity to sound, light' etc., while some others may suffer from hyposensitivity. Likewise, some may exhibit 'odd body moments', while some may spin objects or flap their hands frequently.

Children with autism may show some degree of difficulty with sound, vision, touch, taste, smell, or balance and body awareness (Kern et al. 2006; Kern et al. 2007). The child may be hypersensitive (may overreact to sensory stimuli) or hyposensitive (may underreact to sensory stimuli) (Crane et al. 2009). Sensory sensitivities may change the way people with autism

experience the world (Nguyen, 2006). Daly et al. (2007, p.7) quoted an example of this shared by an individual with autism, ‘I was also frightened of the vacuum cleaner, the food mixer and the liquidizer because they sounded about five times as loud as they actually were’. The condition was elaborated on by another quotation from the same booklet (2007, p.9) that, ‘the sensory overload caused by bright lights, fluorescent lights, colours and patterns makes the body react as if being attacked or bombarded, resulting in such physical symptoms as headaches, anxiety, panic attacks or aggression’.

Presentation of signs and symptoms may vary from individual to individual; it is not necessary for all children with autism to have all of the difficulties described above (Crane et al. 2009; Kern et al. 2006; Nguyen, 2006). Some children may experience some of these, while others may not have any of them at all (NAS, 2012). (See Appendix-C for the possible presenting symptoms and signs for an individual with autism.)

2.3.5. Restricted, repetitive, stereotypical behaviours and interests and their impact

Some individuals with autism exhibit stereotypical behaviours while others may have special interests of an intense nature (Janzen, 1996; NICE, 2012). They are likely to become very upset if they are asked to stop doing their favourite activity in order to do something else (NAS, 2012). For example, they may show great distress if their favourite toy or object has been taken from them.

In addition, some individuals may not like change in their routine, while some may appear inflexible in terms of interests and actions (Jordan, 1999; Wilkes, 2005). They may prefer order and routines, may prefer to eat exactly the same food or wear the same clothes, etc., and may like to travel the same way to school, the park or a takeaway. These children may not tolerate change (Bogdashina, 2003). For example, they may get extremely distressed on changing their environment, moving house or school, moving or changing objects, furniture, toys or anything else (Daly et al. 2007).

Apart from the factors listed above, executive functioning has also been related to these behaviours. Executive functioning was defined by Ozonoff et al. (1991, p. 1083) as 'the ability to maintain an appropriate problem solving set for attainment of a future goal; it includes behaviours such as planning, impulse control, inhibition of prepotent but irrelevant responses, set maintenance, organised search, and flexibility of thought and action'. A lack of executive functioning could be related to some of the behaviours described above such as difficulty accepting change and problem solving.

2.4. The ways autism affects the child's family

Cavaleri et al. (2010, p.56) quoted Yatchmenoff (1998), 'parenting can be stressful under usual circumstances, but the caretaking demands placed upon parents of youth with mental health challenges are often magnified'. A similar view was presented by Meltzer (2010) and Vacca (2013) who said that raising a child has its frustrating moments, but parenting a child with autism multiplies those times and parents often experience high levels of

stress and frustration. Research indicates that the stress of having a child with autism is greater than the stress of having a child with another diagnoses or chronic illness (Debrowska and Pisula, 2010; Eisenhower et al. 2005; Estes et al. 2009; Pisula, 2007). Moreover, a higher level of parenting stress reduces the positive effects of professionally delivered interventions (Davis and Carter, 2008; Osborne and Reed, 2008).

Indeed, developmental disabilities directly and indirectly affect the child and their caregiver. The amount of care required by a disabled child appears to impact upon multiple aspects of family functioning, including the stress specifically associated with parenting (Duarte et al. 2005; Sivberg, 2002). An individual with autism may not express their basic wants or needs in a manner that we would expect. When parents cannot determine their child's needs, all are left feeling frustrated (Midence and O'neill, 1999; Benderix et al. 2006). In addition, maladaptive behaviours may prevent families from attending events together; not being able to do things as a family can impact upon the marital relationship (ASAF, 2013; Brobst et al. 2009).

Having a child with a disability is likely to have an impact on the social and emotional adjustment of family members. The Ministries of Health and Education, New Zealand (2008, p.12) stated that 'the needs of those who share their lives with people with ASD are extensive … Their additional needs for support must be considered to ensure that they, too, enjoy social inclusion to the degree that other community members take for granted'.

A child with autism may present endless challenges to family members, including aggressive and self-injurious behaviours, impulsivity, hyperactivity, rituals, severe communication deficits, as well as a need to face the response of others (Ingersoll and Hambrick, 2011; Konstantareas and Papageorgiou, 2006; Osborne and Reed, 2009; Tomanik et al. 2004). Parents of children with ASD often feel additional responsibilities associated with their child's illness. This may be due to the additional care required by the child, and many other associated factors. Additional time to learn about the problems associated with the condition and appropriate ways to deal with the child may take up time (Cavaleri et al. 2010). They may also have to implement the child's treatment at home, dispense medications, and intersect with multiple systems such as the child's therapies and the approaches followed at school. The additional responsibilities may lead to stress that has adverse effects on both the child and the family (Osborne and Reed, 2009; Suppo and Floyd, 2012).

Siblings of the child may also need to cope with changes in family roles, structure and activities, feelings of guilt and shame, and loss of parental attention, which may also affect their wellbeing and functioning (Hastings, 2003; Hastings et al. 2009; Kaminsky and Dewey, 2002). Pilowsky et al. (2004) added that some previous studies found maladjustment, anxiety, social dysfunction and isolation in siblings of children with autism in 4% to 24% of the families in their study. Parental stress has also been linked to the onset and worsening of behavioural problems and greater school difficulties. Cavaleri et al. (2010) added that parents may suffer from depression or may

have a harsh parenting style, negative parent–child interactions or decreased involvement with their child.

2.5. Need and importance of information or training provided for parents

Davis and Carter (2008) and Pisula (2011) indicated that parents have to face a number of challenges when parenting a child with special needs. They need appropriate guidance on dealing with their children. When the guidance and training is not provided to parents, they have to use a process of trial and error in order to find the appropriate skills to assist in their children's development and education, which is a stressful and lengthy process (Boyd, 2002). Research has further highlighted that failure to intervene effectively early on results in a lifelong course with numerous problems (Wilkins and Matson, 2009). These problems are compounded further by the fact that considerable resources are needed to deal with them resulting in increased stress on the family (Wang et al. 2012). Thus, the development of effective support services to assist families in the care of children with developmental disabilities is of obvious importance (Shields, 2001; Wachtel and Carter, 2008).

Ingersoll and Gergans (2007) and Ingersoll and Schreibman (2006) indicated that parent training offers several important benefits for the child and family. They added that parent-implemented intervention leads to better generalization and maintenance of skills. Moreover, as a result of transferring appropriate information and skills to parents, the research reported reduced parental stress, increased parental optimism and increased parent leisure or

recreation time (Baker et al. 2002; Moes and Frea, 2002; Patterson et al. 2012; Tonge et al. 2006). Additionally, if families are provided with relevant and effective information, guidance and training, it is likely to assist them with care, sustain the family unit and lead to reduced levels of stress, thereby preventing possible family breakdown and the need for long-term, out-of-home care (Higgins et al. 2005).

In recent years, parent information and training programmes have emerged as an important component in the array of services that have been developed to support families who have a child with autism (Benson et al. 2008; Granpeesheh et al. 2009; Hall and Graff, 2010). When parents are given proper guidance and training to deal with their children at a young age it results in a positive impact on the child's later functioning (Drew et al. 2002; Eaves and Ho, 2004; Rickards et al. 2009). Parent training has also been shown to improve the quality of life for the family by decreasing parental stress (Suppo and Floyd, 2012). Other improvements in children noticed in the research included improvements in communication, social skills and behaviour as a result of parent training (Bondy and Frost, 2002; Chaabane et al. 2009; Rocha et al. 2007). Moreover, Matson et al. (2009) in their study indicated the positive impact of parent materials or parent training programmes. As a result of the training, parents showed significant decreases in reports of symptoms of depression, parent and family problems, overall family stress, and dissatisfaction with the family's adaptability. Drew et al. (2002) added that parent training may lead to more child gains overall.

Shields (2001) reported that parents of children with autism have a great need of support in the period after their child's diagnosis has been given. However, many generalist professionals (such as GPs and health visitors) have only a limited understanding of the specific needs of these children and their families. Staff working in generic children's services may also find that their usual strategies and materials are poorly suited to the child with autism. Over recent years there has been an increase in parent training programmes that enable parents to capitalize on working in the child's natural environment (Koegel, 2000; Marshal and Marinda, 2002; Schertz and Odom, 2007).

On the other hand, Charman and Stone (2006) argued that the intervention that includes the family of the child results in more effective outcomes. As parents are the first to teach many things to their child their role is very crucial in managing the many symptoms associated with autism. The benefit the child gets from any kind of intervention directly correlates with the parents' participation in carrying on the intervention strategies at home and in a variety of community settings. Researchers have found that early interventions at two or three years of age that involve parents can play a major role in moderating the severity of ASD (Benson et al. 2008; Eikeseth et al. 2009; Matson and Smith, 2008).

Similarly, Chandler et al. (2002) and Luiselli et al. (2000) stated that research has indicated improvement in a child's socialisation and reciprocal communication as a result of empowering parents. Cumine et al. (2000,

p.47) quoted Peacock (1996) that through using the EarlyBird project training parents of children with autism it has recognised that structured intervention, offered as soon as possible after diagnosis, is extremely beneficial for such children.

Solomon et al. (2007) indicated that giving training to parents can help transfer strategies to the child at home and also improve parent–child relationships through this process. Research reveals that children with autism can progress better if the intervention focuses on the strengths and weakness of the child. If it accounts for the nature of autism it may result in reducing the occurrence of many problematic behaviours as well as in improving a child's communication and socialisation. Bogdashina (2005) made the point that autism contains its own language characteristics and means of learning. Therefore, the parent or the instructor needs to learn this before attempting to deal with the child.

The Ministries of Health and Education, in New Zealand (2008, p.3) indicated that 'many adults with autism believe that positive family involvement and support help individuals with autism develop the skills necessary to be as successful as possible as adults'. They (2008, p.12) further reported that 'effective educational programmes for parents and families lead to improved outcomes both for people with ASD and their carers and families'. In other words, providing appropriate information, guidance and training to parents of children with autism is considered to be an essential component of the child's welfare (Drew et al. 2002; Hall and Graff, 2010).

2.6. Methods of providing appropriate information to parents of children with autism

There are several methods by which appropriate information can be provided to parents of children with autism. These are described in a number of ways by different authors e.g. Suh (1999) indicated four methods of providing information to an audience, i.e. text, audio, video, and face-to-face medium. On the other hand, the methods of providing information have also been divided into the categories of print media, electronic media (Public Health Agency of Canada, 2011), printed materials, websites and the internet, parent education courses, discussions and exchange of information, audiovisual materials (Samadi and McConkey, 2011), verbal suggestions, video tapes, information handouts, parent held records, other teaching techniques (e.g. modelling, role play, etc.), group well visits (Glascoe et al. 1998). The above methods are discussed in this part of the chapter, under the categories of 'direct' and 'indirect' methods of providing information to parents (Sudsawad, 2007).

a. Direct or interpersonal communication: interactive methods which include face-to-face communication, training or workshops, home visits, group discussions, and counselling. These methods are generally useful in teaching complex skills that need two-way communications between the parent and the professional (Cunningham et al. 2009; Public Health Agency of Canada, 2011; Samadi and McConkey, 2011).
b. Indirect communication: also known as passive dissemination strategies (Farmer et al. 2011). These include all forms of information

provision which do not require a direct or interpersonal communication as follows:

i) Print: including leaflets, booklets, pamphlets, posters and other written materials. They may also include CDs or DVDs containing text. Websites, internet, articles, forums and other similar medium for providing information may also be included in this category. They are generally considered best for providing a timely reminder of essential information (Public Health Agency of Canada, 2011; Samadi and McConkey, 2011).

ii) Broadcast: including radio and television. These methods are generally useful in raising awareness about a disability. They provide broad coverage for communication of information by reaching a large number of target audiences in a quick and efficient way (Glascoe et al. 1998; Public Health Agency of Canada, 2011).

iii) Other audio video communication: including CDs, DVDs, YouTube videos, etc. (Public Health Agency of Canada, 2011).

2.6.1. Direct or interpersonal communication

Interpersonal communication is a very powerful and effective way of providing information to parents of children with disabilities. Some examples of interpersonal communication include face-to-face communication, seminars, trainings or workshops, home visits, group discussions, and counselling (Farmer et al. 2011; Public Health Agency of Canada, 2011). It is any type of verbal or non-verbal communication where the information

provider gives the information to the target audience in such a way that they are both physically present at the same location.

Some research has suggested that the direct or interpersonal method of transferring information to parents of children with mental health problems is a useful source of health information (Cunningham et al. 2009). Seminars and training events for practitioners are an effective way of communicating research findings (Grimshaw and Eccles, 2008; Grimshaw et al. 2012). The events should include time for participants to share their ideas about the subject area. Glascoe et al. (1998) in a review of 114 articles on this issue found that verbal suggestions are effective for conveying brief, concrete information when parents are not stressed, whereas modelling and role playing appear especially useful when confronted with problematic parenting or child behaviour.

2.6.1.1. Advantages

One of the major benefits of this method of communication is that it is useful for people with low literacy and limited understanding, and is often the first communication between parents and an information provider (Public Health Agency of Canada, 2011). It is an active, interactive and most efficient method of knowledge transfer (Barwick et al. 2005; Johnson, 2005; Grimshaw et al. 2012). It may allow for an exchange of information, sharing of ideas, and an immediate feedback from the receiver, and enables the target audience to grasp information in an explicit manner by letting them clarify any misunderstanding (Cunningham et al. 2009; Farmer et al. 2011;

Grimshaw and Eccles, 2008; Grimshaw et al. 2001; Harmsworth et al. 2000; Public Health Agency of Canada, 2011).

2.6.1.2. Drawbacks

It can be an expensive and time consuming method of providing information (Harmsworth et al. 2000; Woodfield, 2002). It puts demand on resources, and needs a trained and qualified professional or provider for each interpersonal interaction who understand the needs of the target audience (Farmer et al. 2011; Grimshaw and Eccles, 2008; Grimshaw et al. 2001; Grimshaw et al. 2012; Public Health Agency of Canada, 2011).

2.6.1.3. A few examples of this approach

Organisations working to support ASD children and their families around the world have widely used this method of direct communication to provide information to parents of children with autism. A few examples are provided below:

The EarlyBird project (NAS, UK)

EarlyBird is a three-month programme offered as soon as possible after diagnosis by NAS, which caters for six families at a time. It combines group training sessions for parents with individual home visits. It aims: to support parents in the period between diagnosis and school placement, to help them understand the nature of autism and its effect on their child's life, to empower parents and help them facilitate their child's social communication and appropriate behaviour within the child's natural environment, and to help parents establish good practice in handling their child at an early age so as

to pre-empt the development of inappropriate behaviours (NAS, 2010; Shields, 2001).

It is sometimes misunderstood by lay people as an intervention programme only, but, having attended lectures on this programme delivered by the NAS certified professional registered to carry out this training in Wales, UK, and also having access to the materials provided to participants in the training, the researcher found that it also provides essential information to parents which they may need soon after diagnosis. The characteristics of autism, the symptoms that a child may present with and the ways to handle these are well covered and it appears a very informative and useful training to be provided soon after diagnosis.

The ACCESS project (Autism NI, Northern Ireland)

ACCESS, a six week (Autism NI, 2010) or three week (Autism NI, 2013) parent training programme is designed for parents and carers who have received a recent diagnosis of ASD for their child. It aims to enable parents and their families to recognise the child's existing skills and strengths, to obtain the practical and emotional support they require; to better equip parents and carers to understand their child, his or her autism and the 'shape' of services they will require.

Omid project (Iran)

Samadi (2011, p.1027) stated that a parent education programme 'Omid' (based on the findings of their research project and the Keyhole Early

Intervention project developed by ‘Autism NI’ Northern Ireland's Autism charity) has been developed which is under trail at present. In the first phase of the programme parents are provided with post-diagnosis information and advice via some booklets and a resource kit. The second and third phases of the programme include parent training workshops and home visits, while the fourth phase comprises training of professionals who work with such children in pre-school.

Mother Child Programme (AFA, India)

A non-governmental organisation in India, ‘Action For Autism’, offers a three-month parent training programme called the Mother Child programme. 10 to 15 parents are trained together with their children (AFA, 2013; Malhotra and Vikas, 2005).

2.6.2. Indirect communication

As discussed above, the following all provide information to parents which do not require a direct or interpersonal communication.

2.6.2.1. Printed educational materials

Printed educational materials (PEMs) are widely used in dissemination strategies to improve knowledge, awareness, attitudes, skills, practice and patient outcomes (Bull et al. 2001; Farmer et al. 2008; Giguere et al. 2012; Grimshaw et al. 2004). Glascoe et al. (1998) in a review of 114 articles on the subject found that written information can be useful for addressing more complex issues. Traditionally they are presented in paper formats such as

monographs, publication in peer-reviewed journals and clinical guidelines, and appear to be the most frequently adopted method for disseminating information (Farmer et al. 2011, p.1).

As discussed above, information can be provided to parents of children with disabilities using any type of communication that involves the written word (Barwick et al. 2005). This can involve both formal and informal communication. A key distinction between written communication and face-to-face communication is that feedback from the receiver may not be immediate. Some examples of this medium include leaflets, booklets, clinical guidelines, pamphlets, posters and other written materials. Of these, booklets, leaflets and clinical guidelines are among the most frequently adopted methods for disseminating information (Bero et al. 1998; Freemantle et al. 2000; Giguere et al. 2012; Grimshaw et al. 2001).

However, print medium is not confined to words physically printed on paper and may include online articles, forums, information on websites, text based CDs and DVDs, etc. (Cunningham et al. 2009; Public Health Agency of Canada, 2011). Grimshaw and Eccles (2008, p.13) added that PEMs are defined as the 'Distribution of published or printed recommendations for clinical care, including clinical practice guidelines, audiovisual materials, and electronic publications. The materials may have been delivered personally or through mass mailings'.

Although, these are considered passive dissemination strategies, Grimshaw et al. (2012, p.7) indicated that 'printed educational materials are commonly used, have a relatively low cost and are generally feasible in most settings'.

2.6.2.1.1. Advantages

An important consideration of PEMs is that these are a commonly used method of providing information to patients, caregivers, professionals and other relevant personnel (Bero et al. 1998; Bull et al. 2001; Farmer et al. 2011; Freemantle et al. 2000; Giguere et al. 2012; Grimshaw, 2001; Kreuter et al. 1999). They allow information to reach a large and geographically dispersed audience, and are generally feasible in most settings (Grimshaw et al. 2004; Grimshaw et al. 2012). Additionally, they are convenient, easy to produce and cost effective (Harmsworth et al. 2000; Kreuter et al. 1999; Law et al. 2004; Yale Center for Clinical investigation, 2010).

Another benefits of written communication is that it can be used to document what has been said or agreed to (evidence based), and can be used to target motivation when written as a 'persuasive communication' (Public Health Agency of Canada, 2011). It can also be used to clarify ideas, to avoid misunderstandings, and is particularly useful to increase awareness, knowledge, attitudes and skills (Barwick et al. 2005; Farmer et al. 2008; Grimshaw et al. 2001; Law, Kertoy and the CanChild Dissemination Committee, 2004). Additionally, it has the advantages of allowing skilled readers to absorb information at their own pace, and to retain the item for future reference (Ganguly (UNESCO PALDIN), 2007).

2.6.2.1.2. Drawbacks

In printed educational materials there is room for misunderstanding and obscurity (Farmer et al. 2011; Kreuter et al. 1999). These provide a one-way flow of written information which is generally ineffective in changing practice (Barwick et al. 2005; Bero et al. 1998; Grimshaw et al. 2012; Johnson, 2005;). In addition, using web-based sources of knowledge transfer for parents of children with disabilities in developing countries might result in reaching a limited audience due to poverty, limited IT literacy and power failure in resource poor settings (Edejar, 2000; Heeks, 2005; NCDDR, US, 2005; O'Farrell et al. 1999; Westbrook and Boethel, 2005). Additionally, paper or web-based information may result in approaching a limited audience by excluding the population with low literacy skills, and excluding people with limited vision (Freemantle et al. 2000; Ganguly (UNESCO PALDIN), 2007; Public Health Agency of Canada, 2011; Samadi and McConkey, 2011).

2.6.2.1.3. A few examples of this approach

Examples include booklets, leaflets and books published by government agencies e.g. a parent education booklet published in 13 regional languages by the government of India (see section 2.7 of this chapter), or non-governmental organisations (NGOs) worldwide (see chapter 6). Examples also include web-based information provided by NGOs worldwide, such as Autism NI; Autism Speaks, US; ASAF; Box of Ideas, by the Dyscovery Centre, UK and NAS, UK.

2.6.2.2. Broadcast

The broadcast medium is also an effective way of providing information to a target audience. This methods is generally useful in increasing awareness about a disability (Public Health Agency of Canada, 2011). Glascoe et al. (1998) stated that this medium can be helpful for broadening parents' range of interests. Conversely, PEMs and interpersonal mediums of communication are more effective in providing focused and in-depth information to the target audience.

Some examples of include radio and television programmes. As discussed above these mediums are useful in raising awareness, but if used for training purposes may have some limitations. They are fast-paced mediums where listeners or viewers generally have to acquire information at the pace set by the broadcast (Health Canada, 1998). Therefore, it may not always be effective because this medium ignores the user's capacity to absorb information and retain it for future reference (Public Health Agency of Canada, 2011). Thus special care should be taken in designing television or radio programmes for parents of children with disabilities.

2.6.2.2.1. Advantages

The advantages of the broadcast medium as discussed by Grimshaw et al. (2004), Health Canada (1998) and Public Health Agency of Canada (2011) include the ability to overcome some of the language and literacy barriers to communication, the ability to enable the user to use it at the place of their

convenience, and the ability to reach a large and geographically dispersed audience.

2.6.2.2.2. Drawbacks

One drawback of using this medium is that it does not offer an interpersonal interaction, thus there is a room for misunderstandings, obscurities and ambiguity (Public Health Agency of Canada, 2011). Additionally, developing programmes can involve a considerable amount of time and financial resources (Ganguly (UNESCO PALDIN), 2007; Health Canada, 1998).

2.6.2.3. Other audio and video communication

Another method of communication to parents of children with disabilities is though audio and video communication. With this type of communication information is recorded to be listened to or viewed by the receiver at a set time or any time of their choosing (Health Canada, 1998). It combines characteristics of some of the other methods of providing information to a target audience such as printed materials and interpersonal communication, but can be used as an alternative form of communication (Public Health Agency of Canada, 2011).

Some examples include a parent's interview, case studies, intervention approaches or counselling made available on CDs, DVDs and YouTube videos. Podcasts and videos are useful for sharing information in an attractive and easy way (Schnellinger et al. 2010). A lot of information can be

provided using this method of communication so that the receiver can go over it at their convenience and as many times as they like.

It should be as carefully designed as a radio or television broadcast with deliberate attention to the types of voices used, the speed of message delivery, repetition of key points, avoidance of background noise, etc. Use of graphics and action sequences to ‘show’ viewers instead of just ‘telling’ them, can also be a useful strategy that may increase the efficacy of the medium

(Ganguly (UNESCO PALDIN), 2007; Public Health Agency of Canada, 2011).

2.6.2.3.1. Advantages

The advantages of using these mediums as summarised by Health Canada (1998), Public Health Agency of Canada (2011) and Schnellinger et al. (2010) include, allowing the user to review it at the place and time of their choosing, to repeat it as many times as they like, to learn or gain information at their own pace, and to retain the item for future reference. Other advantages are that it can be used to improve knowledge, attitudes and skills, permits reaching a geographically dispersed audience (Grimshaw et al. 2004), and is a cost-effective method of providing information when compared to interpersonal communication or broadcast media (Ganguly (UNESCO PALDIN), 2007).

2.6.2.3.2. Drawbacks

These mediums may result in approaching a limited size of audience by excluding the resource poor population and may not be suitable for people with low IT literacy (Ganguly (UNESCO PALDIN), 2007). Additionally, as they do not offer an interpersonal interaction there is a room for misunderstanding and obscurity (Health Canada, 1998; Public Health Agency of Canada, 2011).

2.6.3. Conclusion

The purpose of providing information, its content and the target audience, are important considerations for selecting a specific method of information provision to that audience, and for successful knowledge translation (Public Health Agency of Canada, 2011). The needs and preferences of the target audience are important considerations when selecting a method to provide information to parents of children with mental health problems (Cunningham et al. 2009). The Ministries of Health and Education, New Zealand (2008, p.12) stated that 'provision of information on ASD is seen as crucial by parents and families. It should be available in various formats and take into account differing needs, both geographic and cultural'.

In a review of 114 articles on the issue, it was found that:

> In selecting among parent education methods, it is helpful to recognize that various outcomes can be expected from each approach. Selection among methods should be made and tailored according to the needs and characteristics of parents and the topic at hand. All 'approaches, if selected wisely and applied well, offer families needed assistance that has proven effectiveness in improving children's and families' health and well-being (Glascoe et al. 1998, p.5).

2.7. Provisions for ASD children and their families in developing countries with particular respect to India

2.7.1. Introduction

When the researcher started working on this project no data was found on the provisions for ASD children and their families in Pakistan or on the prevalence of ASD in Pakistan from any authentic source. The absence of sound data related to child and adolescent mental disorders, and available health resources for the conditions in Pakistan was also indicated by WHO (2005, pp. 9-15). In the next section an effort has been made to present the relevant information available in order to gain a general understanding of the provision for children with mental health problems within a Pakistani context, where unavailability of data did not permit particular conclusions about ASD children and their families to be drawn.

As there was limited information regarding the situation in Pakistan, an understanding was gained regarding the provision for children and their families in countries with similar economic and cultural backgrounds.

Other developing countries were considered, but with a greater focus on India, as India, Pakistan and Bangladesh have been one country for centuries. Although the subcontinent partition into two separate states – India and Pakistan – happened in 1947 (CIA, US, 2013), the cultural characteristics developed over centuries might take time to change if so required. The Indian subcontinent has one of the world's oldest civilizations (Ministry of Minority Affair, Govt of India, 2011) which flourished during the

3rd and 2nd millennia B.C. (CIA, US, 2013). Certain traditions and cultural characteristics of the subcontinent are different from the western world (Bharath, 2010; Malhotra and Vikas, 2005; Sharan and Saxena, 2006). In the subcontinent social relatedness has been greatly emphasized (Malhotra and Vikas, 2005). The joint family system, the roles of men and women in a family, wedding ceremonies, and many other customs are similar in India and Pakistan. Even the national languages of the counties are spoken in a similar way. According to Education Scotland (2013) and Lewis et al. (2013), Urdu is mutually intelligible with standard Hindi. Written Hindi and Urdu are different but the spoken words are almost identical. The US Central Intelligence Agency (CIA) (2013) stated that according to the 2001 census in India, 'Hindustani is a popular variant of Hindi/Urdu spoken widely throughout northern India but is not an official language'. Urdu on the other hand, is one of the official languages of India (Census Organization, Govt of India, 2001; Fatihi, 2003; Sarfraz et al. 2011). As culture and 'language is a unifying factor which holds together groups of people by providing them an identity (Ministry of Minority Affair, Govt of India, 2011, p.1)', the Indian context was explored to estimate figures for Pakistan.

Another reason for including the Indian context was its' recognition about the disability and work as compared to other developing countries of the region (Action for Autism, AFA,2008). Malhotra and Vikas (2005, p.5) stated that 'though the quality and quantity of research which has been carried out in India is not very good; it is still the best among all the developing countries'. AFA (2008, pp.78–79) also indicated that 'members of AFA regularly present

training workshops these have been in cities throughout India, and in Bangladesh, Nepal, Pakistan, Dubai, and the United Arab Emirates'.

2.7.2. Provision for ASD children and their families in developing countries

2.7.2.1. Mental health workforce in developing countries

Sharan (2008, p.1) stated that in low- and middle-income (LAMI) countries 'attention on child and adolescent mental health workforce has been lacking. There is a dearth of sub/super-specialists in child and adolescent mental health …. Moreover, there is a severe shortage of even the general mental health practitioners in most LAMI countries'. WHO (2005, p.21) also pointed out the issue that the 'child and adolescents psychiatrists are relatively rare outside developed countries and there are very few who are fully trained in the developing countries'.

WHO (2005) stated that in India, the number of psychiatrists is at 0.2, psychiatric nurses at 0.05, psychologists at 0.03, and psychiatric social workers at 0.03 per 100,000 population. Sharan and Malhotra (2007, p.18) further elaborated the situation by stating that 'in a low-income country like India … just about 100-125 psychiatrists are devoting time specifically to child and adolescent mental health (approximately 20 are trained in child and adolescent psychiatry and about 100 have developed it as an area of special interest)'. The data about Pakistan indicated that the total number of registered psychiatrists equals no more than 320 (Syed et al. 2006), with only less than ten trained child psychiatrists for the whole of Pakistan (Tareen et al. 2008).

In 2010 health expenditure in India was 4.1% of GDP, almost double that of Pakistan at 2.2% of GDP, but their expenditure was less when compared with the rest of the world; Pakistan was at 188th position in country comparison, whereas Bangladesh was at 176 and India at 164 (CIA, US, 2013).

Shortage of trained mental health professionals is a common problem in developing countries (Malhotra and Vikas, 2005). Sharan (2008, p.1) reported that 'children and adolescents needing mental health care are mostly attended by general physicians … pediatricians, and mental health professionals; who usually lack specific training in child and adolescent psychiatry'.

2.7.2.2. Prevalence of ASD in developing countries

AFA (2008, p.14) reported that 'there have as yet been no epidemiological studies of autism conducted in India, or in any comparable region of the world in order to provide a definitive estimate of either prevalence or incidence …. Thus, while there are no studies from India, the numbers are likely to be similar'. Unavailability of definitive data on autism was reported for UAE and Bangladesh as well (Autismi- ja Aspergerliitto ry, 2013; Chaudhary, 2012; Ethirajan, 2011). Elsabbagh et al. (2012) in a report on the global prevalence of autism to WHO also indicated the unavailability of definitive data or epidemiological studies on autism in the developing countries. Samadi and McConkey (2011, p.2) also indicated that 'there is

limited information on the identification of children with this condition in developing countries in which services for children with special needs are less developed'.

The above indicates that even in other developing countries of the region estimates are provided about the prevalence of individuals with ASD.

2.7.2.3. Diagnosis of ASD in developing countries

Sharan (2008, p.1) stated that in developing countries, 'for most young people, mental health… problems are either unrecognized or inadequately treated'. Malhotra and Vikas (2005) further indicated that 'parents, who need help, do not know where to go. They keep shuttling between general physicians, paediatricians, psychologists and psychiatrists before getting the proper diagnosis and treatment'. AFA (2008, p.24) reported that in India 'there is no system of screening that 'catches' all young children with a developmental delay or disorder'. Parents have to rely on referrals from their medical professionals, on word of mouth, through newspaper articles or other sources (AFA, 2008).

Limited understanding of the condition among relevant professionals may lead to wrong diagnoses in these countries. Malhotra and Vikas (2005) stated that a majority of such children are not diagnosed or misdiagnosed due to lack of awareness among the general public and to some extent even among the health professionals. Autismi- ja Aspergerliitto ry, a Bangladeshi autism organisation, (2013) stated that there is a lack of knowledge about

ASD even among doctors. Very often children are misdiagnosed and some are given antipsychotic drugs by psychiatrists. AFA (2008, p.15) stated that ‘many children who have mental retardation in addition to autism may in the past have only received a diagnosis of mental retardation … when awareness of autism in India was so low. On the other end of the spectrum, many children with good communication skills may have been diagnosed with schizophrenia, ADHD, or completely missed altogether and simply considered to be ‘unusual’ children’. Autismi- ja Aspergerliitto (2013) stated about Bangladesh, while Malhotra and Vikas (2005) added about India and other developing countries, that the cases which get the proper diagnosis and treatment are actually only a very small proportion of the total number of cases prevalent in the community.

In addition to misdiagnosis and no screening facilities being provided for the whole population in developing countries, a single professional diagnosis is common in some settings. In developed countries diagnosis is usually carried out by a team of health and education professionals, but such facility is constrained in developing countries by the limited number of health professionals and a lack of a trained workforce. AFA (2008, p.21) stated that ‘in India, with the large numbers of cases that physicians have to deal with, as well as the dearth of such physicians in many places, usually a single professional is involved in making the diagnosis. This could include a clinical psychologist, speech therapist, special educator or other professional who deal with children with autism on a regular basis’. Malhotra and Vikas (2005) stated that there is an urgent need to establish specialised centers for

identification of such children as well as to train health professionals who are involved in care of persons afflicted with autism.

2.7.2.4. Number of children diagnosed with ASD in developing countries

Samadi and McConkey (2011) stated that children diagnosed with autism in developing countries such as in Iran are fewer than those diagnosed in developed countries.

A similar situation in India indicates that:

> Greater awareness of autism in India among medical professionals has played a role in the increase of children diagnosed as autistic … Even with this increased awareness, the number of individuals receiving a diagnosis in India is still far behind that in higher income countries. And, within India, there are fewer children being diagnosed in rural areas as compared to those in urban areas of India (AFA, 2008, pp.15-16).

2.7.2.5. Services provided for ASD children and their families in developing countries

Elsabbagh et al. (2012, p.176) stated that in developing countries, 'very little attention is paid to developmental disabilities at policy and implementation level and as a result budget allocations and human resource deployment is directed away from these programs.' Malhotra and Vikas (2005) added that although health professionals have been providing treatment and care to children with autism and their parents in India, there have been no serious efforts by the government to establish centres which would provide specialist

care. They (2005) further added that most of the cases are seen and managed at overcrowded government general hospitals or psychiatric hospitals.

Limited provision for such children and their families by government agencies was noticed in Iran, Malaysia and Bangladesh as well. Samadi and McConkey (2011, p.2) stated that in Iran children with ASD are usually 'diagnosed by medical doctors either privately or through child and family clinics provided by voluntary organisations'. Day centre placements are available through the Iranian State Welfare Organisation, but only for children with severe difficulties. In addition, these services are only available in big cities and probably only for more affluent families. Provision for adult services is mostly through private or voluntary organisations that also rely heavily on parental fees. Samadi (2011, p.1027) added that 'autism is still so new for the Iranian professionals and service providers and there is still a long way ahead of the policy makers and service providers to offer satisfactory and sufficient services. Services are still not sufficiently developed, therefore parents' feelings of uncertainty and the frustrations of not knowing how best to help their child is a part of this story.'

The Malaysian Psychiatric Association (2010) indicated that many children with autism do not have access to therapy that can help them lead fulfilling lives. The government centres that provide therapy are located largely in urban areas and the waiting list is long. In addition, the therapist to student ratio is very high, while the programmes carried out by NGOs are out of

reach of people on low incomes due to their high costs. In a report on an international conference on autism, Ethirajan (2011) stated that a spokesperson for Action Aid Bangladesh indicated limited diagnostic facilities in that country. Autismi- ja Aspergerliitto ry, a Bangladeshi autism organisation, further indicated that there are only 20 schools for disabled children in Bangladesh all of which are situated in the capital. In addition, it was noted that facilities for getting a diagnosis and treatment are very scarce.

Elsabbagh et al. (2012, p.176) stated that the 'dysfunctional health systems' of developing countries 'contribute further to lack of service delivery' for such children. 'Where they exist, access to these facilities is also hindered by lack of effective identification and referral programs'. Sharan and Malhotra (2007, p.18) indicated that 'geographic and economic barriers (the majority of relevant professionals are concentrated in large cities either at university centres or inside the private system) further render access to the limited services difficult'. Malhotra and Vikas (2005) added that lack of trained personnel is also a serious handicap. The few private centres which provide specialist care are out of reach of most people. AFA (2008, p.24) further indicated that in many areas of India 'there are no special schools or facilities for children with any disability, let alone children with autism'.

Due to limited resources and limited understanding of the condition among communities and relevant professionals, services provided for ASD children and their families are not adequate according to the needs of the target

audience in developing countries (Samadi and McConkey, 2011). Efforts are made by government and non-government agencies to provide the required support to such children and their care givers (Malhotra and Vikas, 2005). The services provided include diagnostic facility, special schools, occupational therapy and speech therapy. In a few countries, such as India, social skills training, respite care (daytime), parent training, child's intervention by educators (one-on-one sessions several times a week), training manuals, workshops and resource libraries have also been provided (AFA, 2008).

Elsabbagh et al. (2012) and Malhotra and Vikas (2005) pointed out an interesting issue that in developing countries some significant gains have been made through the efforts of NGOs and parents associations. These organisations 'are actively working on creating awareness, services, and advocacy for people with PDD' (Elsabbagh et al. 2012, p.176). Malhotra and Vikas (2005) presented an example that autism was legally recognised as a disorder by the government of India in 1999 through the efforts of these organisations. In addition to promoting awareness among professionals and empowering parents through parents groups, these organisations have also conducted training courses for professional development of teachers in India.

In order to get an in-depth understanding of the services provided by such organisations for ASD children and their families in developing countries i.e. countries with a similar economic and cultural background, or countries in the

same region, a review of the websites of these organisations was carried out (see Appendix D).

This review identified that efforts were made in each country to provide services to ASD children and their families. Although the services might be inadequate and scarce as indicated in the literature review above, yet certain services were provided by organisations working to support such children and their families (see Appendix D). It was noted that many organisations listed in Appendix D provided a school or unit for children with ASD, assessment or diagnostic units and other services including different therapies. A few of them provided consultancy and daytime respite care as well, and some provided a discussion forum for parents and organised workshops for parents and professionals. However, only a few organisations provided information to parents in terms of materials or training.

In spite of the importance of parent education or empowerment as discussed earlier in this chapter, attention has not been paid to it in developing countries (Malhotra and Vikas, 2005). A few noticeable services provided to parents in these countries include a three-month parent training programme: 'Mother Child programme' in India and a parent education programme: 'Omid' in Iran. In China, a three-month parent training programme was offered, but that appeared as an intervention programme based on Applied Behavioural Analysis (ABA). In addition, parent education booklets are published in India by a government agency, the National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and

Multiple Disabilities Act 44 of 1999. These booklets are published in 13 regional languages and sold at a nominal cost by the agency (Malhotra and Vikas, 2005). Additionally, a booklet, *Autistic Spectrum Disorders – A Guide for Paediatricians in India* designed by AFA in 2008, seemed a feasible initiative in a resource poor setting. Although it was designed for paediatricians (aimed to target more than 15,000 registered paediatricians in India), it also contained information that paediatricians could share with families after diagnosis. Thus, it might have worked as a parent empowering tool and at the same time might have helped in increasing the understanding of the condition among medical professionals.

AFA (2008, p.24) on the other hand pointed out that 'increased diagnosis can encourage the establishment of special schools and services (if there is demand, there will be supply)'. Therefore with increased awareness and with more children diagnosed with ASD there is a likelihood of the establishment of appropriate services for such children and their families in the developing world (Elsabbagh et al. 2012).

2.7.3. Conclusion

Provision for children with ASD and their families appears to be limited in developing countries. Very few schools, diagnostic centres, therapy units or other services are found in these countries. In addition, such services, if there are any, are made available in urban areas only and are usually provided by non-governmental agencies. Therefore some of these rely heavily on parental fees and are out of the reach of people on low incomes.

There are no specialised diagnostic centres and appropriate screening or referral system in many such countries. In some areas, children are diagnosed by a single professional e.g. a paediatrician or psychiatrist, and are seen at overcrowded government hospitals. The problem is further compounded by the lack of trained professionals in such regions and limited awareness of the condition among relevant professionals which results in misdiagnosis in some cases. Sources of information for parents are also inadequate and does not meet their needs.

A few initiatives have been taken in this regard to promote awareness among relevant professionals and to provide required information to parents, such as discussion forums, workshops, conferences and information provided via booklets or on the websites by organisations working to support such children. Education and treatment facilities are also provided for such children,but these services do not meet the needs of the target audience, and some of these are segmented efforts. There is a need for an adequate and uniform countrywide provision and further development of services for such children and their families in developing countries.

2.8. The Pakistan context

2.8.1. Historical Background

Pakistan is a sovereign country in South Asia that appeared on the map of the world in 1947. Pakistan has one of the world's oldest civilizations (UNESCO, 2013), the Indus Valley civilization, dating back at least 5,000 years (US Central Intelligence Agency (CIA), 2013). The culture of the region

merged with the Indo-Aryan people on the arrival of the Aryan during the 2nd millennia B.C. (Ministry of Information, Broadcasting and National Heritage, Government of Pakistan, 2013). The territories now constituting Pakistan underwent successive invasions from the Persians, Greeks, Scythians, Arabs, Afghans, and Turks (CIA, US, 2013; UNESCO, 2013). After the conquest of Sindh by Arabs in AD 711, Islam gained a firm hold in the area (Ministry of Information, Broadcasting and National Heritage, Government of Pakistan, 2013). The Mughal Empire flourished in the 16th and 17th centuries until the establishment of the British Empire in the region in the 18th century (CIA, US, 2013). Pakistan gained independence in 1947 when the subcontinent was separated into two independent states – India and Pakistan (Ministry of Information, Broadcasting and National Heritage, Government of Pakistan, 2013; Sustainable Development Policy Institute SDPI, 2008). Pakistan was then separated from East Pakistan, present-day Bangladesh, in 1971 (Ali, 2012).

2.8.2. Geographical information

The official name of the country is The Islamic Republic of Pakistan. It is bounded by Iran in the south west and Afghanistan in the west and north. Pakistan shares its north-eastern border with China and its eastern border with India. The coastline along the Arabian Sea makes up the country's southern boundary (Ministry of Information and Broadcasting, Government of Pakistan, 2012).

Pakistan comprises four provinces; Punjab, Sindh, North West Frontier Province (NWFP), and Balochistan, with an area of 796,095 sq km (CIA, US, 2013). Islamabad is the capital of the country, while the capitals of the provinces are Lahore, Karachi, Peshawar and Quetta respectively (Briney, 2010; CIA, 2013).

2.8.3. Population

The population of Pakistan was 132.35 million in 1998 (according to a population census in 1998): 1998 census data is presented in this section as there was no further census until 2011. The data from the 2011 population census has not yet been published (Population Census Organization, Government of Pakistan, 2013), therefore estimations of population are presented: 173 million in 2010 (UNICEF) and 183 million in 2013 (Population Census Organization, 2013), with an average growth rate of 2.07 % (Ministry of Finance, Government of Pakistan, 2011). With an estimated population of 177.1 million in 2011, it is the sixth most populous country in the world (Economic Survey of Pakistan, 2010-11, Finance Division; Briney, 2010).

According to the 1998 census the Pakistani population consisted of 52% male and 48% female population, with 43% of the whole population under 15 years of age. As almost half of the whole population is under 15 years of age; it is considered a nation of young people. The disabled population is 2.54%, the economically active population is 22%, and the unemployment rate is 19% (1998 census, Population Census Organization, Government of Pakistan).

2.8.4. Languages

Pakistan is a multilingual country with a number of languages being spoken (UNESCO, 2013). Lewis et al. (2013) stated that out of 72 living languages in Pakistan, 13 are institutional, 11 are developing, 38 are vigorous, eight are in trouble, and two are dying.

The national language of the country is Urdu (Asad et al. 2004; Durrani and Hussain, 2010; Sarfraz et al. 2011; UNESCO, 2013; US Department of State, 2010) which is mutually intelligible with standard Hindi (Education Scotland, 2013; Lewis et al. 2013) and much of its formal vocabulary is borrowed from Arabic and Persian (Lewis et al. 2013). Urdu is the language of most print media of the country (Library of Congress 2005).

Pakistan has two official languages which are English and Urdu (CIA, US, 2013; Hussain et al. 2011). English is the language of most government ministries and the Pakistani elite (CIA, US, 2013), but is not widely spoken or understood in the country (Asad et al. 2004; Hussain et al. 2011). Major regional languages include Punjabi spoken by about 48% of the population, Sindhi by 12%, Saraiki (a Punjabi variant) 10%, Pashto 8% and Balochi by 3% (CIA, US, 2013; Hussain et al. 2011).

2.8.5. Culture

The customs, culture and traditions of Pakistan embody hues of the cultures of India, Central Asia and the Middle East (Ministry of Information,

Broadcasting and National Heritage, Government of Pakistan, 2013; Sustainable Development Policy Institute (SDPI, 2008). Although Islam has played a pivotal role in shaping cultural life, the culture of Pakistan is an amalgamation of different cultures as the region has continued to experience immigration from Central Asia and the Middle East since the arrival of the Aryans (Coleman, 2004; CIA, US, 2013; Ministry of Information, Broadcasting and National Heritage, Government of Pakistan, 2013; UNESCO, 2013).

2.8.6. Gender roles and family dynamics

The social and cultural context of Pakistani society is predominantly patriarchal (SDPI and Japan International Cooperation Agency (JICA), 2008; UNESCO, 2013). However, the nature and spread of patriarchy vary across classes, regions, and the rural–urban divide (Coleman, 2004; Population Council, US, 2009; SDPI and JICA, 2008). A study from the Asian Development Bank, Bari et al. (2000, p.2) reported that 'patriarchal structures are relatively stronger in the rural and tribal setting where local customs establish male authority and power over women's lives'. Conversely, women belonging to the upper and middle classes of society have increasingly greater access to education and employment opportunities and have greater control over their lives (Bari et al. 2000).

Although, the constitution of Pakistan gives equal rights to men and women, the country lies among the bottom ten in the global gender gap index (UNESCO, 2013). In addition, women's autonomy levels e.g. mobility,

independent decision making, control over material and other resources, establishment of equitable power relationships within families, etc. in the subcontinent remain among the lowest in the world (Jejeebhoy and Sathar, 2001; United Nations Development Programme (UNDP)'s development index, 2013). Jejeebhoy and Sathar (2001, pp.706–707) found in a study that the autonomy of Indian and Pakistani women is attributed neither to nationality nor to religion, but is strongly conditioned by the social system of the region within the subcontinent.

Gender roles in Pakistan have been shaped by centuries of culture and tradition (Coleman, 2004; SDPI, 2008). Adult males are considered responsible for earning money for the family, while domestic duties are considered exclusively the females' responsibility (Population Council, US, 2009; Sathar et al. 2002; SDPI and JICA, 2008). Bari et al. (2000, p.2) reported that 'male members of the family are given a better education and are equipped with skills to compete for resources in the public arena, while female members are imparted domestic skills to be good mothers and wives'. Despite women's legal right to own and inherit property from their families, there are very few women who have access to and control over these resources (Bari et al. 2000; SDPI, 2008; SDPI and JICA, 2008).

Additionally, women's mobility is strictly constrained (Coleman, 2004). Women, especially young unmarried girls, usually need permission from parents or head of the household to travel to any place including shops, health centres, a relative's or a friend's house, and are generally

accompanied by a male member of the family or an older woman (Bari et al. 2012; Jejeebhoy and Sathar, 2001; SDPI and JICA, 2008). The primary reasons for travel restrictions all relate to tradition, family reputation and protection of girls from 'eve teasing', i.e. sexual and physical harassment by men (Bari et al. 2012; Coleman, 2004; Sathar et al. 2002). Although women face controls on their movements, the restrictions on mobility gradually decrease as the age increases (Sathar et al. 2002; SDPI and JICA, 2008).

Gender segregation is another tradition prevalent in the society. Many families do not favour co-education for their girls, and mixing up of girls and boys even in social gatherings (Coleman, 2004; SDPI and JICA, 2008). Some even prefer that the female family memebers should be seen by a female doctor (Coleman, 2004). Therefore, considering the cultural and traditional norms, the government has established schools and colleges exclusively for girls with female teachers to provide equal educational opportunities and to promote female literacy in the country (Ministry of Education, Government of Pakistan, 2009; SDPI and JICA, 2008; UNESCO, 2013). In the health sector, a major initiative by the government in this regard was the recruitment of lady health workers (the term used in the country) to provide basic health care including family planning to women at the grass-roots level (Bari et al. 2000; Ministry of Information and Broadcasting, Government of Pakistan, 2012). See tables 2A and 2B in the following sections for number of lady health workers in the country and also of educational institutions established exclusively for girls.

Social relatedness is greatly emphasized in the subcontinent (Milhotra and Vikas, 2005). Although the nuclear family system is becoming popular in Pakistan, the extended family system is considered as the basis of social structure and is adopted by the majority of the population (Population Council, US, 2009; Sathar et al. 2002). People are respected because of their age and position (Kwintessential Ltd, UK. 2012). Older people, both men and women, are viewed as wise and are granted respect and a higher status in the family and community (SDPI and JICA, 2008), and loyalty to the family comes before other social relationships, even business (Kwintessential Ltd, UK. 2012). Families are quite large by western standards, often having up to six children (Sathar et al. 2002).

2.8.7. Education

The constitution of Pakistan sets out an egalitarian view of education by speaking of providing education to all citizens irrespective of gender, caste, creed, or race (SDPI and JICA, 2008). According to Article 37(b), it is considered the responsibility of the government 'to remove illiteracy and provide free and compulsory secondary education within a minimum possible period' (Ministry of Education, Government of Pakistan, 2009, p.16).

The Ministry of Education (2009, p.16) states that in contrast to this vision for education, there has been 'little commitment' to achieve these goals. As a consequence, Pakistan's education system is 'afflicted with fissures' that have created parallel systems of education (private schools and Madrasas) and has 'performed poorly on the criteria of access, equity and quality'.

UNESCO (2012) indicated that Pakistan's spending on education is very low and has reduced from 2.6% of gross national product (GNP) in 1999 to 2.3% of GNP in 2010. The country ranks 113 out of 120 countries in the Education Development Index (UNESCO, 2012).

School education is organised in a 5+3+2+2 model: primary education (5 years, age group generally 6–10 years), middle/elementary education (3 years), secondary education (2 years), and higher secondary education (2 years) (Ministry of Education, Government of Pakistan, 2009; Nordic Recognition Information Centres, 2006). Pre-primary or early childhood education (age group 3–5 years) has also been recognised by the government recently (Ministry of Education, Government of Pakistan, 2009).

There are 225,135 schools with an enrolment of 33,688,629 students, offering education up to higher secondary level, and 129 universities with an enrolment of 803,507 students including both public and private sector (Ministry of Education, Government of Pakistan, 2008). Detail of institutions with reference to level and gender is provided below.

Table 2A: Educational institutions by level and gender 2008-09

	Public sector				**Private sector**			
	Boys	Girls	Mixed	Total	Boys	Girls	Mixed	Total
Pre-Primary	-	-	-	-	12	40	775	827
Primary	88,692	47,481	-	136,173	660	768	16,084	17,512
Middle	8,039	7,371	-	15,410	754	646	23,824	25,224
High	6,421	3,307	-	9,728	1,152	1,065	12,049	14,266
Higher Secondary	612	424	-	1,036	167	242	997	1,406
Inter colleges	80	59	18	157	105	184	256	545
Degree colleges	424	419	84	927	41	156	188	385
Total	104,268	59,061	102	163,431	2,891	3,101	54,173	60,165

Source: Ministry of Education, Government of Pakistan, 2009

A survey report produced by Lynd, published by UNESCO (2007) indicated that Pakistan has a net primary enrolment rate of 62%, decreasing to 35%, 20% and 10% for mid-elementary, secondary and higher secondary respectively. In addition to low school enrolment, drop-out rates are too high (Ali, 2012; Ministry of Education, Government of Pakistan, 2009; UNESCO, 2013). Akram and Bashir (2012) stated that 34% of those enrolled in schools at the primary level leave without education. UNESCO (2012) reported that although Pakistan's primary net enrolment ratio rose to 74% in 2010, it has the world's second highest number of children out of school, reaching 5.1 million in 2010.

The literacy ratio of age 10+ was 43.92% as reported in the 1998 census, with 54.81% male and 32% female literacy rates (Population Census Organization, Government of Pakistan). As discussed above, no population census was conducted from 1998 to 2011, and the results of 2011 population census are not yet available (Population Census Organization, 2013), therefore estimates vary in literacy rates as well. The US CIA's (2013) estimate indicates 49.9% adult literacy in 2005, with 63% for the male population and 36% for the female population. According to an estimate from UNICEF, the total adult literacy rate in 2010 was 56%. Another estimate from the Economic Survey of Pakistan 2010–11 indicates that around 57.7% of adult Pakistanis are literate. Male literacy is 69.3% while female literacy is 45.2%.

2.8.8. Economy

Briney (2010) stated that Pakistan is a developing nation with an underdeveloped economy. Agriculture accounts for more than one-fifth of output and two-fifths of employment, and textiles account for most of Pakistan's export earnings (CIA, US, 2013). About 22% of the population live below the international poverty line of US$1.25 a day, while 60% of the population live below the international poverty line of US$2 a day (UN's Human Development Reports, 2008).

The CIA, US (2013) stated that the depreciation of Pakistani currency and high inflation have increased the amount of poverty. The Pakistani rupee has depreciated more than 40% since 2007 due to political and economic instability (CIA, US, 2013). The Economic Survey of Pakistan 2010–11 by the Finance Division referred to a report indicating that a 10% rise in domestic food prices in Pakistan for one year could push an additional 3.47 million people below the $1.25-a-day poverty line or worsen the poverty situation by 2.2 percentage points. The Economic Survey also indicated that food inflation in Pakistan has averaged 18% for the last four years which implies a significant deterioration in the purchasing power of the poor.

2.8.9. Challenges

Pakistan is a lower middle income country (The World Bank, 2013) with many challenging problems including illiteracy, poverty and corruption (Briney, 2010; CIA, US, 2013; Coleman, 2004; SDPI and JICA, 2008). The US Department of State (2010) stated that high population growth, low

literacy levels and high unemployment rates are key concerns, especially in rural areas. Further challenges include year-on-year consumer price inflation, including food and utility prices, extreme poverty and underdevelopment (CIA, US, 2013; The Economic Survey of Pakistan 2010-11). The US Department of State (2010) further indicated that high population growth and low levels of spending on social services have contributed to persistent poverty and unequal income distribution.

2.8.9. Healthcare system in Pakistan

Pakistan is a resource poor country with regard to public spending on health and education (Lasi et al. 2012). According to the Library of Congress (2005, p.9), Pakistan's health indicators, health funding, and health and sanitation infrastructure are generally poor, particularly in rural areas. SDPI and JICA (2008, p.ix) reported that 'the health facilities for the masses are over-burdened and the quality of health services suffers greatly. The public healthcare system suffers as doctors prefer giving services to the affluent'. About 19% of the population is malnourished – a higher rate than the 17% average for developing countries – and 30% of children under age five are malnourished (Library of Congress, 2005).

On the other hand, the Secretary of the Ministry of Economic Affairs and Statistics for Pakistan has argued (National Health Accounts Pakistan, 2005-06) that Pakistan's expenditure on health has increased remarkably in recent years, but according to figures supplied to WHO for its international overviews these are still very low compared to international standards.

Mubbashar and Saeed (2001) have also given arguments in favour of the Pakistani health system by saying that from modest beginnings in 1947 when there were only three mental hospitals in Lahore, Hyderabad and Peshawar, and a psychiatric unit at the Military Hospital in Rawalpindi, psychiatric units have gradually been established in all the medical colleges of the country. The CIA US (2014) indicated that in 2012 the health expenditure of Pakistan was estimated to be 2.7% of GDP and in country comparison pakistan stands at 183rd position out of 191 countries listed in their table. Mubbashar and Saeed (2001) added that the mental health budget is 0.4% of the health budget.

Table 2B: An overview of total public health facilities in Pakistan

Hospitals	916
Dispensaries	4,600
Basic Health Units (BHUs)	5,301
Maternity & Child Health Centres	906
Rural Health Centres (RHCs)	552
Hospital Beds	99,908
Doctors (registered)	113,206
Dentists (registered)	6,127
Nurses (registered	48,446
Paramedics	23,559
Lady Health Workers	6,741

Source: Ministry of Information and Broadcasting, Government of Pakistan (2012)

A slight difference was found in the number of facilities provided by different sources. This may be due to a difference of reporting year or data collection source. For example, the total number of hospitals in Pakistan was 916 as reported by Ministry of Information and Broadcasting, 972 by Economic Survey 2010–11 (Finance Division), and 965 by the Ministry of Health.

Health facilities at national level as reported by the Ministry of Health, Government of Pakistan (2007) include 965 hospitals, 4,916 dispensaries, 371 tuberculosis (TB) clinics, 1138 Maternal and Child Health Centres (MCHCs), 595 Rural Health Centres (RHCs), 4872 Basic Health Units (BHUs), 105,005 beds in hospitals and dispensaries, 1515 population per bed; 1475 population per doctor, and 107835 registered doctors out of which 19,623 doctors registered as specialists.

WHO (2011) reported on the basis of the latest available data that there are about eight physicians per 10,000 of the Pakistani population; however regional averages deviate slightlyfrom the national averages. Some regions have eleven physicians per 10,000 of population, while some have less than the national average. The CIA (2014), indicated that in 2009 the density of physicians in Pakistan was estimated to be 0.81 physicians per 1,000 population. Whereas in 2012 the hospital beds density of Pakistan was 0.6 beds per 1,000 population, if compared with the rest of the world it ranked 175th out of 191 countries listed in their table. Pakistan's total expenditure on health was 2.7% of GDP in 2012, quite low when compared with the whole world (183rd position in country comparison, lower than Bangladesh at 169th and India at 159th) (CIA, 2013).

2.8.10. Provision for individuals with disabilities in Pakistan

The Japan International Cooperation Agency (JICA, 2002, p.5) stated in a report on disability in Pakistan that 'persons with disabilities are mostly unseen, unheard and uncounted persons in Pakistan … face multiple social,

economic, physical and political handicaps, hampering their freedom of movement in society.' Lack of public awareness about the potential of people with disabilities acts as a barrier to their acceptance and participation in the society (Akram and Bashir, 2012; Lasi et al. 2012; Mactaggart and Murthy, 2013; Thomas and Thomas, 2002). Idrees and Ilyas (2012) stated that most of the public places in the country, like shopping malls, railway stations, hotels, cinemas and educational institutions, do not cater for the mobility and access needs of people with disabilities.

According to UNICEF (2011), discrimination against children with disabilities stems from multiple sources including ignorance, prejudice and cultural norms, which in turn lead to stigma and entrenched social exclusion. the Special Talent Exchange Programme (STEP) and Sightsavers International, Pakistan (2006, p.11) stated that 'stigma remains in society at large, within communities, and even, in many cases of uneducated segments of society, within families who see a disabled person as a loss of productive potential and a drain on family resources'.

2.8.10.1. Prevalence of disabilities in Pakistan

There is an absence of reliable data on the prevalence and status of people with disabilities in Pakistan (JICA, 2002; UN Economic and Social Commission for Asia and the Pacific (ESCAP), 2009; UNESCO, 2000; UNICEF, 2003b). Although government has made efforts to collect data on disability in the population censuses, these attempts have been criticised for the lack of definitional clarity, inconsistent use of categories, types of

disability covered and also concerns regarding under-reporting due to issues of social stigma (Ahmed, 1993; Mactaggart and Murthy, 2013; Singal et al. 2009; UNICEF, 2003b).

The proportion of disabled population by the nature of disability was presented in the following table (Table 2C) based on the 1998 population census.

Table 2C: Disabled Population by Nature of Disability

		(In percent)						
Administrative Unit	Total Disabled Population	Blind	Deaf/Mute	Crippled	Insane	Mentally Retarded	Having Multiple Disability	Others
Pakistan	3,286,630	8.06	7.43	18.93	6.39	7.60	8.23	43.37
Rural	2,173,999	7.92	7.53	20.52	5.94	7.32	8.23	42.55
Urban	1,112,631	8.32	7.24	15.81	7.28	8.15	8.22	44.97
(Out of this proportion of population, 1.82 million resides in Punjab)								
Punjab	1,826,623	8.48	8.17	20.83	6.75	7.87	8.07	39.84

Source: 1998 Census, Population Census Organization, Government of Pakistan

In 1998 the disabled population of Pakistan was 3.28 million (2.54% of the total population) with 8% blind people, 7.4% deaf/mute, 18.9% crippled, 6.3% insane, 7.6% mentally retarded, 8.2% with multiple disabilities, and 43.3% people with some other disability (terms used in census).

The prevalence of disability recorded in the 1998 census is considered a gross underestimation (Afzal 1992; Ahmed, 1993; Ahmad and Yousaf, 2011; Rukanuddin, 2003; STEP, 2013; UNICEF, 2003b). Singal et al. (2009) stated that a survey done in the 1980s by WHO reported 11.3 million people with

disabilities in Pakistan (7% of the total population). Additionally, in the National Policy for Persons with Disabilities (2002), the Government of Pakistan itself acknowledged that the disability prevalence rates obtained in the 1998 Census are under-estimates and do not represent the true picture. Therefore, the National Policy was formulated using the WHO disability prevalence estimates of 10% of the total population (National Policy, Government of Pakistan, 2002).

2.8.10.2. Factors contributing to a rise in number of people with disabilities in Pakistan

Lack of adequate health care, poor immunization, consanguinity, poverty, malnutrition and road accidents are factors that might contribute to a rise in the numbers of people with disabilities in Pakistan (Afzal, 1992; Singal et al. 2009; Thomas and Thomas, 2002; UNICEF, 2003b).

2.8.10.3. Education and rehabilitation services

Rehabilitation services are mainly provided by the government (UN ESCAP 2009). In addition, many NGOs and some international organisations including the International Labour Organization (ILO), JICA, UNESCO and UNICEF are also actively supporting disability in Pakistan (STEP, 2006).

Both government and NGOs provide medical rehabilitation services, special education services, vocational training and placement of individuals with disabilities (Awan, 2005; Sajjad et al. 2009; UNICEF, 2003b). Starting from scratch, Pakistan has made significant progress in all relevant areas since the establishment of the Directorate General of Special Education (DGSE)

and the National Trust for the Disabled (NTD) at the federal level in the 1980s (Hussain et al. 2011; National Policy, Government of Pakistan, 2002). Free medical treatment in government hospitals, free primary and secondary education and free access to certain assistive devices has been provided for people with disabilities by the government (Chandio, 2007; Mactaggart and Murthy, 2013; STEP, 2006). In addition, a 2% quota is reserved by the government for the employment of people with disabilities (Asia-Pacific Development Centre on Disability (APCD), 2011; National Policy, Government of Pakistan, 2002).

UNESCO (2013) reported that the country possesses a total of 51 institutions for the disabled, all located in urban areas. Of these, 50% offer education at the primary level, 15 offer at mid-level and the rest offer secondary education. Total enrolment in these institutions is 4,295 (65% boys, 35% girls).

Even though the Government of Pakistan is committed to providing free education to individuals with disabilities, vast majority of children with disabilities in Pakistan are not in school (Mactaggart and Murthy, 2013, p.9), and those that are, face stigmatisation and discrimination from other students, teachers and community members (Idrees and Ilyas, 2012). In addition, only up to 4% of the total number of school-going age students with disabilities is enrolled in various schools (Singal et al. 2009; UN ESCAP, 2007; UNICEF, 2003b) and the drop-out rates are high (Thomas and Thomas, 2002).

It is also noted that the facilities provided do not cater for the needs of the whole population (JICA, 2002; National Policy, Government of Pakistan, 2002) and quality of services provided in general is poor (Ahmad and Yousaf, 2011; Hussain et al. 2011). UN's ESCAP (2002, p.5) reported that people with disabilities, especially women and those in rural areas, are 'disproportionately undereducated, untrained, unemployed, underemployed and poor'. JICA (2002, p.6) stated that 'employment opportunities for persons with disabilities are very limited and so they are a financial burden for their families'.

2.8.10.4. Legislation

'The National Commission on Education (1959) for the first time placed the education of special children on the agenda of the government' (Ahmad and Yousaf, 2011; Akram and Bashir, 2012; UNICEF, 2003a, p.20). But the first ordinance for rehabilitation of people with disabilities was passed by the government in 1981 (Asia-Pacific Development Centre on Disability, 2011; Chandio, 2007); it is called 'the Disabled Persons' (Employment and Rehabilitation) Ordinance, 1981' (Ordinance 1981, Government of Pakistan).

2.8.10.5. Self-help groups

A few associations of disabled people and self-help groups have been formed in Pakistan, but their activities are limited to provision of services (Thomas and Thomas, 2002).

2.8.10. Provision for children with ASD in Pakistan

Unfortunately, no data was found on the provision for ASD children and their families in Pakistan or on the prevalence of ASD by any authentic source when the researcher began work on this project. WHO (2005, p.15) indicated 'the absence of sound data related to child and adolescent mental disorders', and (WHO, 2005, p.9) available health resources for the conditions in Pakistan. Therefore an effort was made here and in the preceding sections to present the relevant information available about the provision for people with disabilities in Pakistan, and also draw on the available figures for those with ASD in other developing countries to estimate the provisions for children with ASD and their families in Pakistan.

Tareen et al. (2008) stated that Pakistan is reported to have the world's highest rates of mental retardation, where the prevalence estimates vary from 19.1/1000 for serious mental retardation to 65/1000 for mild mental retardation. Syed et al. (2007) added that 10 to 16 percent of the general population of the country suffer from mild to moderate mental health illness. The prevalence of ADHD in Pakistan has been found to be around 2.49% (Imran, 2007), but no data were found on the prevalence of ASD in Pakistan. Due to the lack of a population census since 1998, an estimation of population and prevalence of disabilities has been calculated since then.

ASD is an emerging field in Pakistan, though not a well-known term; even awareness of autism is in its initial stages. Being a developing country with many competing demands on its resources, knowledge and understanding of

ASD is limited. The problem of how to support children with ASD and their parents is compounded by poor awareness on the part of parents, teachers and health professionals (Syed et al. 2006). Knowledge and understanding of ASD is increasing slowly, but the number of children diagnosed with ASD is also increasing as is the demand for educational provision for these children.

The total number of registered psychiatrists in Pakistan was reported to be less than 320, with only two registered child psychiatrists (Syed et al. 2006) or less than ten registered child psychiatrists for the whole population (Tareen et al. 2008). According to WHO guidelines, at least two child psychiatrists should work full-time for every 60,000 children (Tareen et al. 2008), but unfortunately, only between two and ten child psychiatrists work for approximately 57.44 million Pakistani children (Tareen et al. 2008; Syed et al., 2006). Imran et al. (2009, p.895) reported that 'lack of mental health services for this huge young population poses a significant problem'. WHO (2005, p.21) also pointed out the issue that the 'child and adolescents psychiatrists are relatively rare outside developed countries and there are very few who are fully trained in the developing countries'.

2.9. Conclusion

Powell and Jordan (2012) said that autism is a complex and often puzzling disorder. Parents find it hard to understand the needs, behaviours and problems of their child with autism. The child not only faces the problem of understanding his parents properly, but also fails to communicate his needs,

desires and emotions to his parents due to the impairment of perception, interaction and communication (Bogdashina, 2005; NAS, 2012). When the needs of the child remain unmet, the environment remains unpredictable for the child, and the people around him appear alien due to their different way of learning, behaving and communicating; the difficulties of the child may get worse with time (Nguyen, 2006). Additionally, research indicates that the amount of care required by a disabled child appears to impact upon multiple aspects of family functioning (Cavaleri, et al. 2010; Davis and Carter, 2008), and it directly or indirectly affects the child and their caregiver (Lennard-Brown, 2006). The problem can be addressed if parents are equipped with the skills for handling their child by keeping in view the nature of autism. Therefore, it is very important for parents to understand their child's strengths, deficits, and ways of learning (Bogdashina, 2005).

Unfortunately, services provided for children with autism and their families are fairly limited in Pakistan and many other developing countries. Very few schools, diagnostic centres, therapy units or other services are found in these countries, usully only in the urban centres. In addition, the screening or referral system is not organised in many such countries. There is a lack of trained professionals in such regions and in some areas children are diagnosed by a single professional e.g. a paediatrician or psychiatrist. Additionally, the knowledge and understanding of ASD is limited, even among relevant professionals, which results in misdiagnosis in some cases. The cases which get the correct diagnosis and treatment are actually only a very small proportion of the total number of cases prevalent in the community

(Autismi- ja Aspergerliittory, 2013; Malhotra and Vikas. 2005; Samadi and McConkey, 2011).

Sources of information for parents are also inadequate for their needs. ‘Parents’ feelings of uncertainty and frustrations of not knowing how best to help their child’ is also reported (Samadi, 2011, p.1027). Although awareness of ASD, total health expenditure, mental health workforce, and services for such children and their families are better in some countries when compared with Pakistan, yet they are inadequate according to the needs of the population (Malhotra and Vikas, 2005; Samadi and McConkey, 2011; Sharan, 2008; Sharan and Malhotra, 2007); whereas the absence of dedicated child and adolescent mental health services in Pakistan has been reported (Imran et al. 2009). The need for tailored evidence-based interventions and parent information materials for these conditions has been emphasized which could easily be integrated into existing systems of care (Samadi, 2011; Tareen et al. 2008), therefore, the present study focused on examining the appropriate method of transferring information to parents of children with ASD in the context of Pakistan.

The following chapter will describe the methods used in the current study, as well as the reasons for its choice.

CHAPTER 3: RESEARCH DESIGN

3.1. Introduction

This chapter presents a discussion and review of the literature undertaken to determine a suitable design for the present study. Beginning with an overview of terms used to describe the framework or process for providing information to parents of children with disabilities, it will present discussion on selecting a suitable design combined with the reasons for deselecting other possible models. It will then provide a review of some studies in the field of autism comprising similar research projects to elaborate further on the reasons for the design choice.

3.2. Terms used to describe the process of providing information to parents of children with disabilities

Methods or strategies for providing information to parents of children with disabilities were discussed in the preceding chapter. These included leaflets, booklets, pamphlets, posters, websites, internet, articles, forums, parent trainings or workshops, home visits, group discussions, counselling, broadcast, CDs, DVDs, and other audiovisual communication (Cunningham et al. 2009; Farmer et al. 2011; Glascoe et al. 1998; Public Health Agency of Canada, 2011; Samadi and McConkey, 2011). The process through which information or a knowledge product, such as printed educational materials, skills-based training, etc., can be provided to patients, their families, professionals or other target groups is also discussed.

Multiple terminologies have been used in the literature to describe all or part of the process of providing information to parents, professionals or other target groups which contribute to the confusion in the field of knowledge and research use (Canadian Council on Learning (CCL) and Social Sciences and Humanities Research Council of Canada (SSHRC), 2008; Lyon, 2010; Ontario Institute for Studies in Education (OISE), 2014). Levin (2008. p.9) elaborated that 'one of the problems in this field is the multiplicity of terms and concepts with large amounts of overlap in meaning but little agreement on which terms should be used when'. Estabrooks and Wallin (2004, p.2) and Levesque et al. (2007) explained that there is an unresolved 'terminological tangle' in knowledge utilization and its related and associated fields e.g. knowledge translation, diffusion, transfer, dissemination, etc. Law et al. (2004) and Zarinpoush et al. (2007) added that the variety of terms and concepts are often used interchangeably. Graham et al. (2006) stated that the situation is further complicated by thousands of definitions for each term which makes it difficult to find a meaningful and consistent definition, and 'by the use of the terms, often interchangeably. Some are used as nouns to describe the entire process … Others are used as verbs to represent actions or specific strategies taken to cause the uptake to occur'. However, regardless of the term, the underlying spirit is the same of trying to make research matter more in policy and practice for organizational and system improvement (Ontario Institute for Studies in Education, 2014).

Some of the terms used to describe the process of providing information to an audience in the healthcare setting are diffusion, dissemination, implementation, knowledge exchange, knowledge transfer, knowledge translation and research utilization (Davis, 2006; Estabrooks et al. 2006; Estabrooks and Wallin, 2004; Graham et al. 2006; Greenhalgh et al. 2004; Kerner, 2006; Law et al. 2004; Levesque et al. 2007; Lyon, 2010; NCDDR, 2007; Natural Environment Research Council (NERC), UK, 2012; SSHRC, 2011; Zarinpoush et al. 2007).

'Diffusion' and 'dissemination' often refer to the promulgation of information or knowledge products (Brownson et al., 2012; Meyers et al., 2012), whereas 'implementation is defined as a specified set of activities designed to put into practice an activity or program of known dimensions' (Fixsen et al., 2005, p.5). An outcome of diffusion is adoption of an innovation, the outcome of dissemination is attempts to use an innovation in practice, while an outcome of implementation is the actual use of an innovation with good results in practice (Brownson et al. 2012; Fixsen et al., 2005; Greenhalgh et al., 2004). The National Implementation Research Network (NIRN), U.S. (2014) stated that implementation includes diffusion and dissemination but is not defined by it.

Diffusion is defined as 'the process by which an innovation is communicated through certain channels over time among members of a social system' (Rogers, 1995, p.5). Diffusion focuses on how generated knowledge is communicated to broader groups (Alberta Health Services (AHS), Alberta

Mental Health Board, 2009, p.6). Dissemination is defined as the act of spreading information widely (Oxford University Press, 2014). Owens (2001, cited in Zarinpoush et al. 2007, p.10) explained that dissemination is a process of knowing your clients and systematically providing them with knowledge, strategies, products and support that can enable them to better solve their problems. Peters (2006) elaborated that dissemination refers to broadcasting information to those vast continents of signification that are not directly interactive. Implementation research is defined as the scientific study of methods to promote the systematic uptake of clinical research findings and other evidence-based practices into routine practice and, hence, to improve the quality and effectiveness of health care (Foy, et al. 2001). Implementation focuses on how to use innovations as intended and achieve the promised results in typical practice settings (NIRN, US, 2014).

Criticism about diffusion is that it is a passive spread of information (AHS, 2009; Greenhalgh et al. 2004). Although, dissemination overcomes this limitation and constitutes active and planned efforts to persuade target groups to adopt an innovation, both the terms lack the actual uptake or implementation of knowledge (Brownson et al. 2012; Fixsen et al., 2005; Greenhalgh et al., 2004). Another concern about these three terms is that they concern a one-way movement of information from producer or sender to potential users or receivers (Zarinpoush et al. 2007, p.10). In addition, they focus on the implementation or spread of the knowledge, but generally do not emphasize the development or quality of that knowledge (Graham et al. 2006).

Other terms used for knowledge use are ‘knowledge exchange’ and ‘knowledge transfer’. Knowledge transfer and knowledge exchange are defined as ‘a set of activities and approaches that are undertaken to move knowledge among those who have interests or needs in it’ (Zarinpoush et al., 2007, p.1). Argote and Ingram (2000, p.151) defined knowledge transfer as ‘the process through which one unit (e.g. group, department, or division) is affected by the experience of another’. They further elaborated that the transfer of organisational knowledge i.e. routine or best practices, can be observed through changes in the knowledge or performance of recipient units. Law et al. (2004, p.1) stated that knowledge transfer is defined as ‘a process by which relevant research information is made available and accessible for practice, planning, and policy-making through interactive engagement with audiences’.

Knowledge exchange is broadly defined as the just-in-time sharing of information and experiences among development practitioners and leaders (The World Bank Institute (WBI), 2014). The Economic and Social Research Council, UK (2014) explained that knowledge exchange is a two-way process where social scientists and individual researchers or organisations share learning, ideas and experiences. Knowledge exchange also refers to activities that help to create and support the conditions and culture that lead to the effective access, implementation, utilization and evaluation of the credible evidence for improved mental health outcomes for children and youth (Levesque et al, 2007).

The difference between knowledge transfer and exchange is primarily the unidirectional flow of knowledge from researchers to practitioners in the case of knowledge transfer (SSHRC, 2011; Zarinpoush et al., 2007), and the two-way movement of knowledge among researchers and practitioners in the case of knowledge exchange (Zarinpoush et al., 2007). AHS (2009) described the concern about knowledge transfer that it is sometimes interpreted as a unidirectional process and first step of disseminating knowledge or information to stakeholders that does not extend to the use of the knowledge. Graham et al. (2006) added that although knowledge transfer is sometimes considered a two-way process, this is not always made explicit.

Zarinpoush et al. (2007, p.5) elaborated that 'knowledge exchange is preferable to knowledge transfer since a two-way flow of information can lead to an ongoing dialogue between knowledge producers and users and create learning opportunities for both groups'. Graham et al. (2006) quoted the UK Particle Physics and Astronomy Research Council (2006), 'successful knowledge transfer involves much more than a one way, linear diffusion of knowledge and skills from a university to industry; it depends on access to people, information and infrastructure.' The Natural Environment Research Council, UK (2012) also emphasized the importance of a knowledge transfer partnership to facilitate the transfer of knowledge. Although, knowledge exchange emphasizes the exchange of information, both the terms exchange and transfer lack the focus on development or creation of knowledge, or the quality of knowledge (Graham et al. 2006).

Another term used for providing information to a target group in a healthcare setting is ‘research utilization’. Estabrooks and Wallin (2004, p.2) said that ‘the term research utilization is commonly used in nursing, although since the 1990’s the term evidence-based practice is increasingly seen.’ Fixsen et al. (2005, p.26) argued that ‘evidence-based practices are skills, techniques, and strategies that can be used by a practitioner’. Evidence-based practices do not refer to implementation, or the process of knowledge transfer, rather these are skills, techniques or knowledge products with proven effectiveness. Fixsen et al. (2005) and NIRN (2014) explained that evidence-based practices (including clinical practice guidelines) are the core intervention components that have been shown to reliably produce desirable effects.

Research utilization is defined as the ‘application of research-based knowledge to improve outcomes’ (Squires et al. 2008, p.14). Estabrooks and Wallin (2004) elaborated that research utilization is a multifaceted concept encompassing different forms of use of research-based knowledge. Squires et al. (2011, p.2) quoted Estabrooks et al. (2003) that research utilization refers to 'that process by which specific research-based knowledge (science) is implemented in practice'. Alberta Health Services (2009) explained that research utilization focuses only on moving research findings into action. Similar to many other terms above, a concern about this term is its general lack of emphasis on the development of the knowledge (Graham et al. 2006).

‘Knowledge translation (KT)’ is a relatively new term increasingly used in healthcare fields to represent the process of getting research findings and knowledge products into the hands of key audiences (Davison, 2009; Grol and Grimshaw, 2003; US National Center for the Dissemination of Disability Research (NCDDR), 2005; Sudsawad, 2007). ‘Coined by the Canadian Institutes of Health Research (CIHR) in 2000’ (Pablos-Mendez and Shademani, 2006, p.82; Sudsawad, 2007, p.1), KT ‘most readily appears in medical and healthcare literature’ (NCDDR, 2005, p.1). It is the science of moving evidence-based research into practice (Curran et al. 2011; Davis, 2006; Estabrooks et al. 2006; Grimshaw et al. 2006; Kerner, 2006; Ottoson, 2009).

WHO also adapted the CIHR’s definition and defined KT as ‘the synthesis, exchange and application of knowledge by relevant stakeholders to accelerate the benefits of global and local innovation in strengthening health systems and improving people’s health’ (WHO, 2005, p.2; WHO, 2012, p.1). Pablos-Mendez and Shademani, (2006, p.81) added that ‘knowledge translation is considered a cross-cutting, non-linear process that involves not only recent research findings but also knowledge that is created from the dynamic interaction of people who come together to solve public health problems, to learn, and ultimately to drive productive change’. Davis (2005) added that knowledge translation has been defined by the 11th Cambridge Conference, 2003, as an ‘interactive, timely and effective process of integrating best evidence into the routine practices of patients, practitioners,

healthcare teams and systems, in order to effect optimal healthcare outcomes and to maximize the potential of the healthcare system'.

KT was considered relevant for the present study due to its extensive use in preparing guidelines and support materials for nurses, healthcare professionals, patients and their care givers (CIHR, 2004; Davis, 2005; Estabrooks et al. 2006; Logan and Graham, 1998; NCDDR, 2005; Sudsawad, 2007; WHO, 2006), and its emerging importance in health care, disability and rehabilitation fields (Davis, 2005; Davis, 2006; Green and Seifert, 2005; Grimshaw et al. 2006; Kerner, 2006; Kothari et al. 2011; Majdzadeh et al.2008; Ottoson, 2009; Pablos-Mendez and Shademani, 2006; Russell et al. 2010; Sullivan and Cen, 2011; Zwarenstein et al. 2006). It is reported that KT is gaining popularity among healthcare professionals and researchers related to disability, rehabilitation research, medicine and public health (CIHR, 2004; Davis, 2005; Davis, 2006; Davison, 2009; Estabrooks et al. 2006; Kothari et al. 2011; Lavis, 2006; NCDDR, 2005; Sullivan and Cen, 2011; WHO, 2006; Zwarenstein et al. 2006).

The knowledge translation models have been very successful in becoming the first choice of many organisations related to health, disability and rehabilitation throughout the world (Kothari et al., 2011; Sullivan and Cen, 2011). NCDDR, US (2005, p.1) has mentioned that 'KT has emerged as an important concept for the US National Institute on Disability and Rehabilitation Research (NIDRR).' Straus et al. (2005, cited in Sudsawad 2007, p.3) also mentioned the use of KT (a concept about moving research-

based knowledge into practice) in rehabilitation. Santesso and Tugwell (2006, p.88) and Davison (2009, pp.76-81) mentioned the use of KT by many international non-governmental agencies as well as by WHO and CIHR, and also by the US Center for Disease Control and Prevention (Kerner, 2006, p.77). Straus et al. (2006, p.3) highlighted that 'funding agencies, policymakers, researchers, and educators have attempted to turn their attention to knowledge translation'. Collisson et al. (2011, p. E366) added that 'governments and funding agencies have placed increased emphasis on KT as a way to optimize the impact of research investments on health outcomes, research products and health service delivery'.

In October 2005, experts met at a WHO meeting in Geneva to discuss the concepts of KT in global health and to develop priorities and mechanisms for KT research and action (Pablos-Mendez and Shademani, 2006; Santesso and Tugwell, 2006). WHO's initiative on KT was intended to promote the application of KT strategies across their various work programmes (WHO, 2006, p.12). It has not only attracted renowned organizations, but has also captured the focus of individual researchers in developed and developing countries. The KT process and strategies have been an attraction for researchers as they provide a framework to improve the outcomes for patients, the consumers of a product or a target group, and also provide guidelines for the effective utilization of research findings (CIHR, 2004; Davis, 2005; Kothari et al. 2011; Logan and Graham, 1998; Majdzadeh et al. 2008; NCDDR, 2005; Sullivan and Cen, 2011; Zwarenstein et al. 2006).

WHO (2006, p.1) documented that 'KT is emerging as a paradigm' to act towards closing the knowledge-to-action gap (Kerner, 2006) which is an important challenge for global health (Pablos-Mendez and Shademani, 2006). Straus et al. (2006, p.3) added, 'healthcare systems around the world are faced with the challenge of improving the quality of care and decreasing the risk of adverse events. Knowledge Translation has emerged as a potential answer to these challenges'.

WHO's Department of Research Policy and Cooperation (RPC), and Knowledge Management and Sharing (KMS) organized meetings on knowledge translation. A KT model was defined in WHO's agenda as:

> Knowledge translation is a cross-cutting approach that covers various domains in health. It is a complex, non-linear process that involves not only recent research findings but also the dynamic interaction of producers and users to bring about change (WHO, 2006, p.12).

Pablos-Mendez and Shademani (2006, p.82) added, 'KT was proposed as an interactive strategy to … address the shortcomings of supply-and-demand-driven research'.

Knowledge translation refers to a comprehensive process that comprises elements of other terms used in the field of knowledge or research use. Graham et al. (2006, p.14), Lyon (2010, p.3) and WHO (2012, p.2) explained that there have been a number of terms used to describe some aspects or elements of the knowledge translation process, including diffusion, dissemination, evidence-based practice, implementation, knowledge transfer,

knowledge/research uptake, knowledge exchange, and research utilization. WHO (2012, p.2) in their report used ‘the term knowledge translation to encompass all the aforementioned terms’.

KT also overcomes some of the limitations of the terms that refer to the process by which knowledge and research findings are implemented in practice. For example, criticism about diffusion is its passive spread of information (AHS, 2009; Greenhalgh et al. 2004), about diffusion and dissemination it is their lack of actual uptake or implementation of knowledge (Brownson et al. 2012; Fixsen et al., 2005; Greenhalgh et al., 2004) and about diffusion, dissemination, implementation and knowledge transfer it is their one-way movement of information from producer or sender to potential users or receivers (Zarinpoush et al. (2007, p.10). Conversely, KT is an interactive, active and planned process that involves all relevant stakeholders, potential users and producers in the process of knowledge creation and implementation (NCDDR, 2005; Sudsawad, 2007).

In addition to other concerns about the terms used to describe the process of providing information to an audience in healthcare fields, a common concern about all these terms is their focus only on moving research findings into action, with little or no consideration of the development or quality of the knowledge. For example, the focus of diffusion, dissemination, implementation, knowledge transfer, knowledge exchange and research utilization is on the spread of information or the implementation and actual uptake of knowledge (Alberta Health Services, Alberta Mental Health Board,

2009; Brownson et al. 2012; Fixsen et al., 2005; Greenhalgh et al., 2004; Social Sciences and Humanities Research Council of Canada, 2011; Squires et al. 2008; Squires et al. 2011; Zarinpoush et al. 2007) with their general lack of emphasis on development of knowledge (Graham et al. 2006). Conversely, KT caters for the creation, synthesis, exchange as well as application of knowledge by relevant stakeholders (Curran et al. 2011; Estabrooks et al. 2006; Landry et al. 2006; Stevens, et al. 2014; WHO, 2005).

This study called for a framework to cover issues related to the development of appropriate support materials for a particular audience (especially for those with disabilities and their families), and the provision of information to that audience in an effective way to promote knowledge use. Therefore, of all the terms used to describe the process of knowledge and research use discussed above, knowledge translation was considered relevant for the present study.

3.3. Selecting a model of knowledge translation

3.3.1. Introduction

After selecting the knowledge translation process for the present study, the next step was to identify the most accepted framework of knowledge translation in the context of this study. Literature on this issue is presented in this part of the chapter.

AHS (2009, p.7) explained that 'several models and frameworks have been put forth to describe and illustrate the knowledge translation process. To date no one model has been generally accepted as superior and many represent different perspectives and areas of emphasis in the knowledge translation process.' As the proposed study aimed to examine the most appropriate method of KT for parents of children with ASD in the context of Pakistan, appropriate frameworks to follow were considered. It called for a research design that would not only indicate the appropriate method of transferring information to an audience, but also provide guidelines on identifying what is appropriate for that audience. In other words, a research design that would cover issues concerning development and implementation of appropriate support materials for a particular audience, especially for people with disabilities and their families.

In view of the nature of this study, the knowledge-to-action (KTA) model of knowledge translation was considered relevant. Reasons for selecting the KTA model for the present study, critique of this model and its KT process are presented below. Other possible models reviewed combined with reasons for rejecting them are also presented in this section.

3.3.2. Promoting Action on Research Implementation in Health Services (PARIHS) framework

3.3.2.1. Introduction

The PARIHS is a conceptual model of KT describing the implementation of research in practice (Bick and Graham, 2010; Damschroder et al. 2009; Helfrich et al., 2010; Kitson et al. 1998; Willin et al. 2006). This model

emphasizes that a successful implementation of research into practice is a function of the interplay of three core elements: (1) the level and nature of the evidence to be used, (2) the context or environment in which the research is to be placed, and (3) the method by which the research implementation process is to be facilitated (AHS, 2009). These three elements have equal importance in determining the success of the research use (Rycroft- Malone, 2004). Evidence is defined as a combination of research, clinical experience, patient experience and local data or information. Key themes in this context are culture, leadership, and evaluation, while the key themes of facilitation are purpose, roles, and skills and attributes (Sudswad, 2007). For each of these core elements there is a range of conditions from a low-to-high continuum (Rycroft-Malone et al., 2002). Each of the elements is positioned on a low-to-high continuum, and the model predicts that the most successful implementation occurs when all elements are at the high end of the continuum (Kitson, et al. 2008).

3.3.2.2. Reasons for deselecting this model for the present study

The PARIHS did not fit the purpose of the present study for the following reasons. Firstly, the emphasis of this model is on the implementation component within the KTprocess (Kitson et al. 1998; Rycroft- Malone, 2004; Rycroft-Malone et al., 2002). 'PARIHS does not discuss elements or factors related to the knowledge creation process, although creation is also an important part of knowledge translation' (Sudsawad, 2007, p.10).

Secondly, it does not provide a clear framework with defined steps to follow to achieve successful KT. Although this framework put emphasis on the evidence-based knowledge context as well as the facilitation, the process by which the high end of the continuum can be achieved is not simplified. Sudsawad (2007, p.10) explained that PARIHS is a highly complex model. It lacks clarity about application of this model in an actual practice environment. One of the limitations of the PARIHS model identified in a critical synthesis of literature is its 'lack of conceptual clarity, specificity, and transparency, which results in different interpretations of PARIHS concepts by different researchers' (Helfrich et al., 2010; Stetler et al. 2011, p.2). Stetler et al. (2011, p.2) added that another limitation of this model is 'lack of inclusion of relevant elements perceived to be critical to implementation and congruent with the main intent of PARIHS'. Therefore, this model was not considered relevant for the present study.

3.3.3. Understanding-User-Context framework

3.3.3.1. Introduction

This framework for KT provides practical guidelines that can be used by researchers to engage in the knowledge translation process by increasing their familiarity with and understanding of the intended user groups (Campbel, 2010; Jacobson et al., 2003). According to this model, five domains should be taken into consideration when establishing interactions with users. Each of these domains includes a series of questions to identify the areas that should be taken into consideration. The domains and their

sample questions are as follows (Jacobson et al., 2003; NCDDR, US, 2005; Schryer-Roy, 2005):

1. **The user group domain** focuses on understanding several aspects of the user group, such as its context, access to information sources, attitudes towards research, etc. Sample questions for the user group domain include:

- In what formal or informal structures is the user group embedded?
- What is the political climate surrounding the user group?
- What kinds of decisions does the user group make?

2. **The issue** focuses on the characteristics and context of the issue intended to be resolved through the knowledge translation effort. Sample questions include:

- How does the user group currently deal with this issue?
- For which other groups is the issue salient?

3. **The research domain** focuses on the characteristics, relevance, congruence and compatibility of already available knowledge products to the user group. Sample questions include:

- What research is available?
- What is the quality of the research?
- How relevant is the research to the user group?
- Does the research have implications that are incompatible with existing user group expectations or priorities?

4. **The researcher–user relationship domain** focuses on the description of relationships between the researcher and the user group. Sample questions include:

- How much trust and rapport exist between the researcher and the user group?
- Do the researcher and the user group have a history of working together?
- Will the researcher be interacting with the designated representative of the user group?

5. **The dissemination strategies domain** focuses on practical strategies for disseminating the research knowledge. Sample questions are as follows:

- What is the most appropriate mode of interaction: written or oral, formal or informal?
- What level of detail will the user group want to see?
- How much information can the user group assimilate per interaction?

3.3.3.2. Reasons for deselecting this model for the present study

This model of knowledge translation was not considered relevant for the present study because it did not provide guidelines on knowledge creation which is an important part of KT (CIHR, 2004; Sudsawad, 2007) and is also a focus of the study. This model lays emphasis on understanding the context of intended user groups and on interactions of knowledge creators and knowledge users (Jacobson et al. 2003) which are other essential components of the KT process (Davis et al. 2003; NCDDR, US, 2005), but the focus of these interactions is on the implementation of existing knowledge. Sudsawad (2007, p.6) argued that ‘additional frameworks that illuminate the mechanisms, considerations, and influencing factors of the

interaction between the knowledge creators and the knowledge users through all steps in the process of knowledge translation are certainly needed'. Therefore, this model was not selected for the present study.

3.3.4. Rogers' Diffusion of Innovation Theory

3.3.4.1. Introduction

'Diffusion theory … has been applied to translate information in a wide variety of disciplines, such as education, public health, communication, marketing, geography, general sociology, and economics' (Campbel, 2010, p.67). Rogers (2003, p.5) defines diffusion as 'the process in which an innovation is communicated thorough certain channels over time among the members of a social system'. According to Rogers (2003), four key elements of the diffusion of innovation process are innovation, communication channel, time and social system.

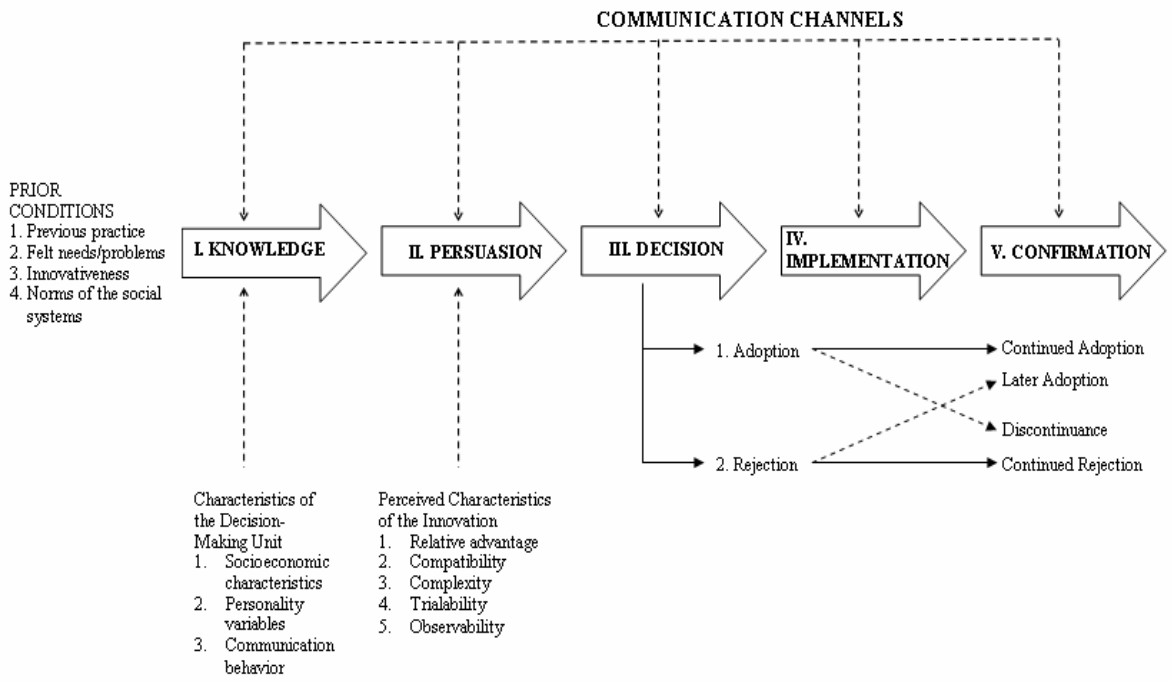
Rogers' theory describes the innovation–decision process and how the perceptions of potential adopters regarding the attributes or characteristics of an innovation influence diffusion of the innovation (Barwick et al. 2005; Helfrich et al., 2010; Rogers et al. 2009; Roman, 2004; Sahin, 2006). Rogers (2003, p.172) described the innovation–decision process as 'an information-seeking and information-processing activity, where an individual is motivated to reduce uncertainty about the advantages and disadvantages of an innovation'.

The innovation–decision process consists of following five stages that potential adopters pass through as they decide to adopt an innovation (Alberta Health Services, Alberta Mental Health Board, 2009; Barwick et al. 2005; Sahin, 2006).

1. **Knowledge** – becoming aware of the innovation
2. **Persuasion** – developing positive attitudes about the innovation
3. **Decision** – making a decision to adopt the innovation
4. **Implementation** –using the innovation
5. **Confirmation** – continuing to use the intervention, adapting the innovation, or abandoning it.

The innovation–decision process has been illustrated in the following figure.

Figure 3A: The Innovation–Decision Process



Source: Rogers, 2003; Sahin, 2006

It is explained in this model that innovations are more quickly adopted when they are: compatible with current values, beliefs and ways of doing things; are seen to be more advantageous than the current practice (relative advantage); are easy to use (low complexity); are used by others (observability); and can be tested before a decision is made to adopt (trialability) (Barwick et al. 2005; Damschroder et al. 2009; Helfrich et al., 2010; Rogers, 1995; Rogers, 2003; Roman, 2004; Willin et al. 2006).

3.3.4.2. Reasons for deselecting this model for the present study

Similar to most models reviewed in this section, Rogers' diffusion of innovation theory focuses on communicating generated knowledge to a broader audience, but does not include the process of knowledge development (Alberta Health Services, Alberta Mental Health Board, 2009; Brownson et al., 2012; Meyers et al., 2012; Rogers, 2003). Other concerns is are its passive spread of information (Alberta Health Services, Alberta Mental Health Board, 2009; Greenhalgh et al. 2004; NCDDR, US, 2005), its lack of actual uptake or implementation of knowledge (Brownson et al. 2012; Fixsen et al., 2005; Greenhalgh et al., 2004) and its one-way movement of information from producer or sender to potential users or receivers (Wiggins et al. 2013; Zarinpoush et al. 2007). For these reasons this model was not considered relevant for the present study.

3.3.5. Stetler Model of Research Utilization

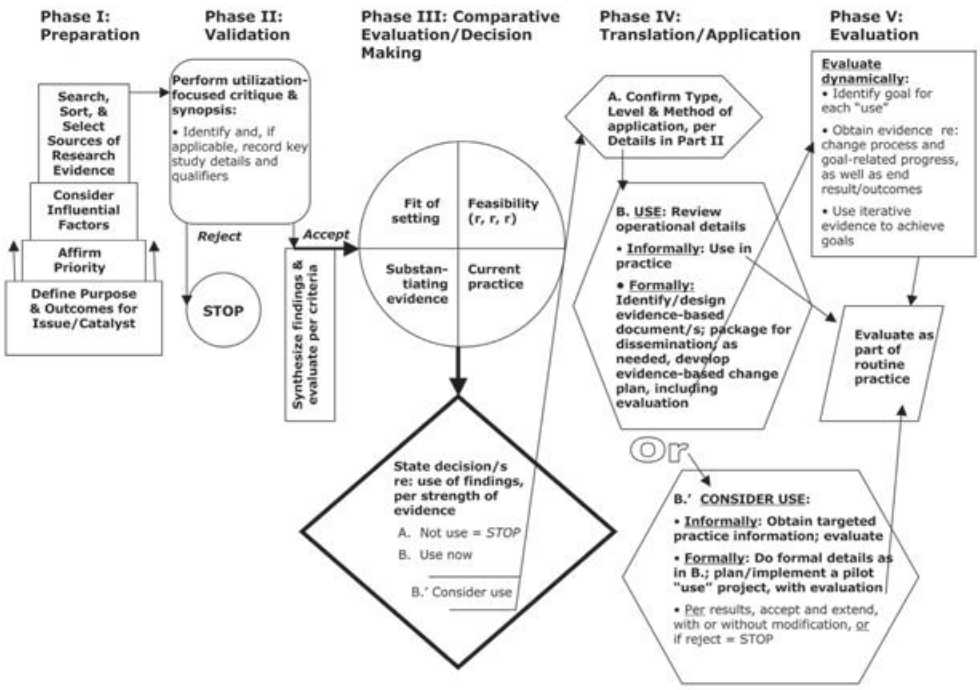
3.3.5.1. Introduction

This model of KT was developed to facilitate safe and effective use of research findings and other relevant evidence (Damschroder et al. 2009;

National Collaborating Centre for Methods and Tools, Canada, 2011; Stetler, 2001), and to be used by individual practitioners for the application of research knowledge into practice (Alberta Health Services, Alberta Mental Health Board, 2009). Like other modesl of research use this model has gone through revisions and the latest version consists of two parts (Rempher, 2006; Stetler, 2001): the first is the graphic model containing five phases of research utilization and the second contains clarifying information and options for each phase (Sudsawad, 2007).

The process of Stetler Model of Research Utilization has been illustrated in the following figure.

Figure 3B: The Stetler Model of Research Utilization



Source: Stetler, et al. 2001

The model is based on the following six basic assumptions (Stetler, 2001, p. 274; Stetler, 2010, p. 59–60):

1. The formal organisation may or may not be involved in an individual's use of research or other evidence.
2. Use may be instrumental, conceptual and/or symbolic/strategic.
3. Other types of evidence and/or non-research-related information are likely to be combined with research findings to facilitate decision making or problem solving.
4. Internal or external factors can influence an individual's or group's review and use of evidence.
5. Research and evaluation provide probabilistic information, not absolutes.
6. Lack of knowledge and skills pertaining to research use and evidence-informed practice can inhibit appropriate and effective use.

The Stetler model of Research Utilization consists of five phases (Stetler, 2001, p. 276; Stetler, 2010, p. 59-60):

Phase 1. Preparation: comprises the selection of research evidence.

Phase 2. Validation: looks for the credibility of research findings and eliminates the non-credible sources of information.

Phase 3. Comparative evaluation/decision making: comprises consideration of research findings in the context of other forms of evidence, whether they fit the setting that is considering implementation, and alignment with current practice and feasibility of adoption.

Phase 4. Translation/Application: consists of decisions about implementation.

Phase 5. Evaluation: comprises dynamic evaluation, the details of which depend on the use decision.

3.3.5.2. Reasons for deselecting this model for the present study

This model did not fit the purpose of the present study because of its lack of emphasis on knowledge creation (Sudsawad, 2007). It puts emphasis on selecting research evidence and validating its credibility, but does not focus on knowledge creation and on involving users of the product in the knowledge creation process (Bick and Graham, 2010; Davis and Nutley, 2008; Nutley et al. 2007; Walters et al. 2004). Like other research utilization models, it focuses primarily on moving research findings into practice (AHS, 2009; National Collaborating Centre for Methods and Tools (NCCMT), Canada, 2011; Stetler, 2001). Another concern about this model is its complexity. Rempher (2006, p.42) argued that it 'uses a prescriptive approach but is complex' and may be difficult for some users to interpret and use.

3.3.6. Ottawa Model of Research Use (OMRU)

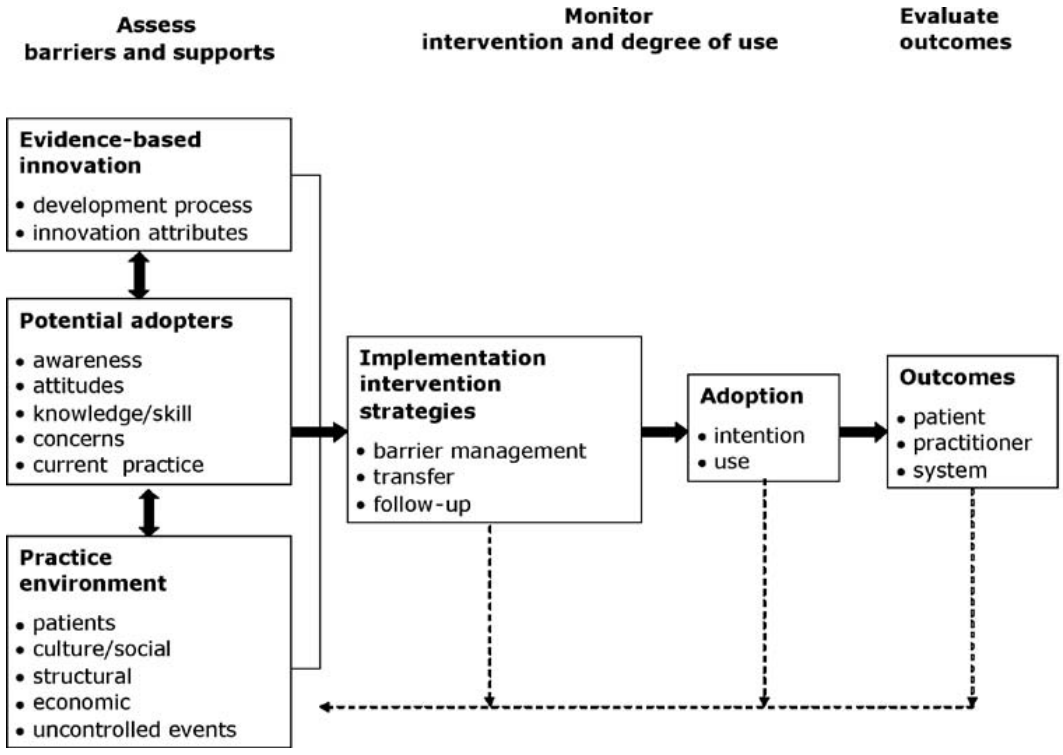
3.3.6.1. Introduction

The Ottawa Model of Research Use (OMRU) provides a comprehensive framework on transferring information to an audience in an effective way (NCDDR, 2007). Santesso and Tugwell (2006, pp.88-89) stated, 'a useful framework to provide direction for planning and guiding knowledge

translation activities is the OMRU developed by Logan and Graham.' Sudsawad (2007, p.7) added that it is an interactive model which has gone through some revisions since its development. This model focuses on moving research findings or evidences into practice (Damschroder et al. 2009; Graham and Logan, 2004). NCCMT (2010) summarised that the OMRU is a knowledge translation model that focuses on the process of transferring research into practice. It is a six-step approach (as described in the figure below) which would be very useful for research utilization, especially in healthcare fields (Barwick et al. 2005; Estabrooks et al. 2006; Logan and Graham, 1998; NCCMT, 2010).

The process of OMRU is illustrated in the following figure.

Figure 3C: The Ottawa Model of Research Use



Source: Graham and Logan, 2003; Graham and Logan, 2004; NCDDR, 2007

The six key elements of OMRU are as follows (Graham and Logan, 2004):

1. Evidence-based innovation
2. Potential adopters
3. The practice environment
4. Implementation of interventions
5. Adoption of the innovation
6. Outcomes resulting from implementation of the innovation

This model relies on the process of assessing, monitoring and evaluating each element before, during and after any knowledge translation activity (Santesso and Tugwell, 2006). Graham and Logan (2004) stated that barrier assessments must be conducted on the innovation, the potential adopters, and the practice environment to identify factors that could hinder or support the uptake of the innovation. The implementation plan is then selected and tailored to overcome the barriers and enhance the supports identified (Graham and Logan, 2004). Sudsawad (2007, p.8) reports that 'the monitoring is ongoing to help determine whether any change in the current implementation or a new implementation plan is required'. The last element of this model is evaluation of the implementation outcomes (Graham and Logan, 2004). It is conducted to determine whether the innovation is producing the intended effect or any unintended consequences (Sudsawad, 2007).

The effectiveness of this model has been indicated in many studies. The feasibility and effectiveness of using the OMRU in actual practice contexts

was supported by findings from a number of studies (Hogan and Logan, 2004; Logan et al. 1999; Stacey et al. 2006; Sudsawad, 2007). In addition, Graham and their research team conducted a theory analysis of all major planned action theories used worldwide and OMRU was also included for analysis (NCDDR, 2007; Tetroe 2007). NCDDR (2007, p.5) indicates that '15 action categories were derived from sorting all of the constructs from all the planned action theories reviewed', and it was worth noting that almost all of these were covered in the OMRU.

3.3.2.2. Reasons for deselecting this model for the present study

Initially OMRU was considered relevant to the proposed study because it is an effective planned action theory in healthcare fields (Hogan and Logan, 2004; Logan and Graham, 1998; Stacey et al. 2006). In addition, it provides a clear framework to follow, with defined steps for the process of KT (Logan and Graham, 1998). It also includes all the important steps of knowledge utilization. A theory analysis indicates that most of the constructs or action categories of all major planned action theories are covered in this model (NCDDR, US, 2007; Tetroe, 2007). Moreover, it includes important elements of the knowledge translation process such as involving stakeholders in the KT process, assessing the needs of target audiences, considering the context, etc. (Bick and Graham, 2010; Davis and Nutley, 2008; Nutley et al. 2007; Walters et al. 2004). Campbell (2010. p.66) stated that OMRU is 'an appropriate knowledge translation method to guide the utilization, implementation, and translation of the communities' research into an action specific to the needs of the community members'.

However, this model was not selected for the present study because it focuses only on knowledge utilization and does not provide detail on knowledge creation. NCCMT, Canada (2010) indicated that this method would be useful for coordinating the implementation of an already existing innovation, policy or program. But for a study that intends to cover material development and its implementation needs a design that provide detail on both of these elements. As the present study intends to cover material development and its implementation, OMRU was not considered relevant.

3.3.7. KTA model of Knowledge Translation

3.3.7.1. Introduction

The KTA model of knowledge translation was devised by Ian Graham (Sullivan and Cen, 2011), CIHR's vice president of knowledge translation, and his research team at the Canadian Institutes for Health Research (Graham et al. 2006; NCDDR, US, 2007; NCCMT, Canada, 2010). An in-depth review of the literature indicated that CIHR's definition of knowledge translation has been considered as a principal conceptual framework to follow (Collisson et al., 2011; Kothari et al. 2011; NCDDR, US, 2007; Sudsawad, 2007). CIHR's work on KT has been regarded by many agencies worldwide and individual researchers such as Collisson et al. (2011), Davis (2005), Graham et al. (2006), Kothari et al. (2011), Lavis (2006), NCDDR, US (2007), NCCMT, Canada (2010), NIDRR, US (2005), Pablos-Mendez and Shademani (2006), Santesso and Tugwell (2006), Sudsawad (2007) and WHO (2006).

3.3.7.2. Theory analysis of planned action theories for the action cycle of knowledge-to-action model

Many action research models and frameworks are used to provide information to an audience in the healthcare field. Graham, Logan, Harrison, Tetroe, Grimshaw and the Knowledge Translation Theories Research Group of University of Ottawa and CIHR conducted a theory analysis of all major planned action theories, frameworks and models in 2006–07 to identify limitations, commonalities and generalizabiliy of these theories (Graham et al. 2006; NCDDR, US, 2007; Tetroe, 2007). Tetroe (2007) briefed that an intensive search that included more than 4000 hits only on Health Science literature was conducted. Different planned action models or frameworks designed to be used to bring about change or to provide information to an audience in healthcare settings from the UK, USA, Canada, Netherlands and a few other places were examined (Graham et al, 2006; NCDDR, US, 2007, p.3). Graham et al. (2006, p.20) reported that many commonalities were found in 60 such theories or frameworks identified by 2006 which are summarised below:

- Identify a problem that needs addressing
- Identify, review, and select the knowledge or research relevant to the problem e.g. practice guidelines or research findings
- Adapt (adjust) the identified knowledge or research to the local context
- Assess barriers to using the knowledge
- Select, tailor (modify) and implement interventions to promote the use of knowledge i.e. implement the change

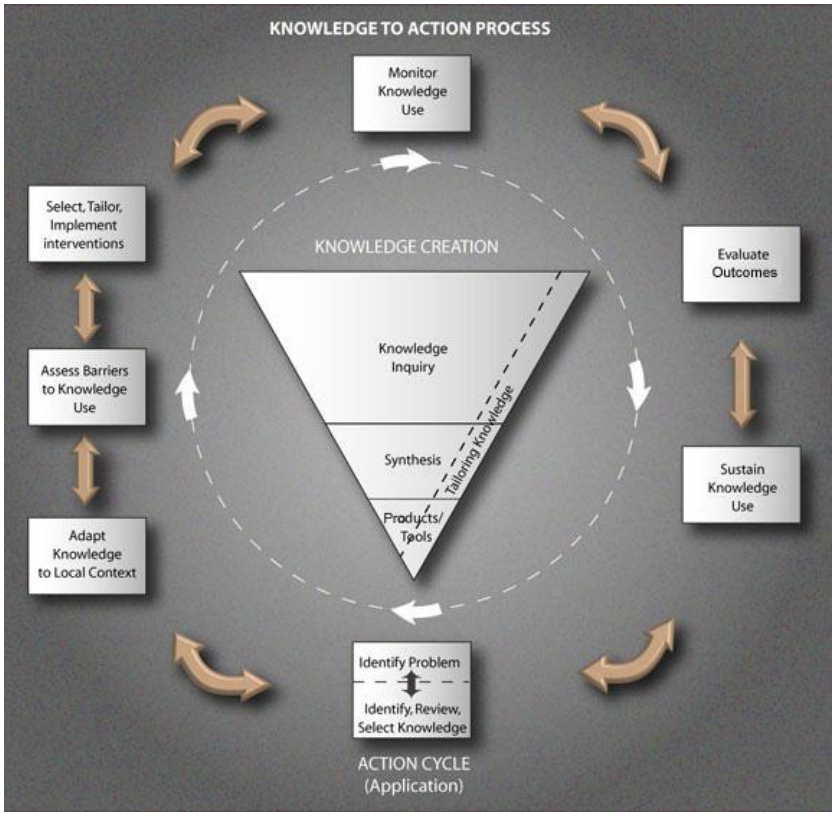
- Monitor knowledge use
- Evaluate the outcomes of using the knowledge
- Sustain ongoing knowledge use.

The action phase of the KTA model was derived from the review of these theories and it included important and common elements of all major planned action theories (Graham et al. 2006). Rycroft-Malone et al. (2011, p.3) stated that ‘the KTA framework is underpinned by action theory and stakeholder involvement, containing a cycle of problem identification, local adaptation and assessment of barriers, implementation, monitoring, and sustained use’.

3.3.7.3. Knowledge translation process of Knowledge-to-Action model

Figure 3D below represents the conceptual framework of the KTA model which comprises a funnel that corresponds to knowledge creation, and an action cycle that represents the process of knowledge application.

Figure 3D: The Knowledge-to-Action model of knowledge translation



Source: Canadian Institutes of Health Research, 2012; Leneis, 2011; Straus and Leung, 2011; Straus et al. 2011.

CIHR (2012) indicated that the knowledge creation funnel conveys the idea that knowledge needs to be increasingly distilled before it is ready for application. The action part of the process can be thought of as a cycle leading to implementation or application of knowledge (Graham et al. 2006).

Ilott et al. (2013, p.2) stated that 'knowledge creation involves finding out what is already known about a topic, tailoring this information and producing tools to support the change in practice'. It is thought that the knowledge becomes refined and more useful for the stakeholders as it moves through

the funnel (CHIR, 2011; Graham et al. 2006). Graham et al. (2006, p.18) added, ‘Another analogy would be to think of the research being sifted through filters at each phase so that, in the end, only the most valid and useful knowledge is left’. While, the action cycle represents activities that, according to planned action theories, are needed for successful knowledge application (CIHR, 2014; Sudsawad, 2007).

It is important to note that the KTA process has been divided into two concepts of ‘knowledge creation’ and ‘action’ for conceptual and illustrative purposes only (CIHR, 2011; Graham et al. 2006). The actual process of knowledge creation and implementation is very complex and dynamic (Alberta Health Services (AHS), Alberta Mental Health Board, 2009; CIHR, 2014). Ilott et al. (2013. p.2) stated that ‘there is constant movement and interaction between the knowledge creation funnel, shown in the centre of the diagram, and the surrounding action cycle’. In addition, the boundaries between the two concepts (of knowledge creation and action) and their phases are fluid and permeable, and the phases of knowledge creation are embedded in the phases of the action cycle (AHS, 2009; CIHR, 2014; Graham et al. 2006).

In a publication by the US National Center for the Dissemination of Disability Research, Sudsawad (2007, p.9) indicated that ‘the relationships between the action phases within the cycle are not unidirectional’. Rather, all phases in the action cycle can influence one another and can also be influenced by the knowledge creation process (Sudsawad, 2007). Graham et al. (2006,

p.18) also reported that, ‘the action phases may occur sequentially or simultaneously, and the knowledge phases may influence the action phases’. Graham et al. (2006, p.21) further added that ‘there may also be feedback between the phases’. For example, the monitoring phase might reveal that the desired results are not achieved at the implementation phase; this would lead researchers to rethink the implementation strategies used and introduce more of the same or different ones to try to improve the uptake of the knowledge (Graham et al. 2006).

Although knowledge creation cannot be separated from knowledge application or the action cycle, these components are explained separately to describe the action taken at each of their phasees (AHS, 2009; CIHR, 2014; Graham et al. 2006).

In summary, the first five phases of the action cycle and all three phases of the knowledge creation funnel are related to identification of the systems’ needs to determine the type of new knowledge required and development of knowledge products that are tailored to the needs of the target audience, local context and potential barriers to knowledge use. Phase five of the action cycle also comprises implementation of knowledge products, while the remaining phases of the action cycle are about monitoring, evaluating and sustaining knowledge use.

3.3.7.4. Critique of the Knowledge-to-Action model

A concern about the KTA model is the link between its two knowledge translation process components – knowledge creation and knowledge

application. McWillain et al. (2009) argued that the KTA framework affords limited insight into how one might combine the 'what' of knowledge translation (that is, evidence and context, as elaborated by the PARIHS model) with the 'how' (that is, the participatory action cycle) of KT. The Canadian Institutes of Health Research (2012) defended the KTA model by stating that the two KTA components have permeable boundaries and knowledge translation is complex and dynamic process. Lyons (2010) also supported the KTA model of knowledge translation. Lyons (2010, p.12) explained that ‘the knowledge translation process is by no means simple, speedy, or straightforward … What may seem like straightforward evidence and/or simple changes can, in fact, be very laborious and even controversial’.

Ilott et al. (2013, p.2) stated that ‘the KTA Process is dynamic – there is constant movement and interaction between the knowledge creation funnel, shown in the centre of the diagram and the surrounding action cycle’. Alberta Health Services, Alberta Mental Health Board (2009) explained that the KTA process is complex and dynamic with no definite boundaries between the two components and their phases. Campbell (2010) added that KTA has an explicit framework in which knowledge creation and application phases may occur simultaneously, and may influence each other.

CIHR (2011) and Graham et al. (2006) also explained that the KTA process has been divided into two concepts of knowledge creation and action for conceptual and illustrative purposes only. In reality the process of knowledge

creation is embedded in the action cycle which is described in the explanation of phases (CIHR, 2011; Graham et al. 2006; Sudsawad, 2007).

3.3.7.5. Reasons for selecting the Knowledge-to-Action model for the present study

The feasibility and effectiveness of the KTA model has been supported by findings from a number of studies. NCDDR, US (2007, p.5) indicated that though measuring and attributing impact is difficult and still in its early stages within the health research field, yet the Canadian Health Services Research Foundation (CHSRF) and the Alberta Heritage Foundation for Medical Research have made arrangements to address this issue by evaluating the impact of the research they fund at CIHR. Therefore, KTA employed in several programmes of CIHR is continually assessed regarding its impact.

Additionally the action phase of the KTA model was derived from an intensive analysis of planned action theories, frameworks and models. It not only uncovered the essential components of action theories tested already, but also looked for the limitation of other theories in use to avoid repeating the flaws already identified (Graham et al. 2006; NCDDR, US, 2007; Tetroe, 2007).

Another distinctive feature of KTA is its comprehensiveness as it covers all the important elements of the knowledge translation process. Bacsu and Smith (2011, p.3) stated that the KTA model ‘offers a holistic view’ of knowledge translation by integrating the concepts of knowledge creation and action. The National Collaborating Centre for Methods and Tools, Canada

(2010, p.2) stated that the 'Knowledge-to-Action process (KTA) is a comprehensive knowledge translation model.' It appears to bridge the gap between 'what is known' and 'what is done' (CIHR, 2012; Davis, 2006; Davison, 2009; NCDDR, 2007; Ottoson, 2009; Pablos-Mendez and Shademani, 2006).

Other models discussed in this chapter focus on some aspects of KT and ignore others. For example, CIHR (2004, p.4) indicated that KT 'is a broad concept that encompasses all steps between the creation of new knowledge and its application to yield beneficial outcomes for society'. While, the OMRU, Rogers' diffusion of innovation theory, Understanding-User-Context framework, Stetler Model of Research Utilization and PARIHS models of knowledge translation focus on the utilization and application of already available knowledge but ignore the creation of new knowledge according the needs of target audiences (Brownson et al., 2012; Damschroder et al. 2009; Estabrooks et al. 2006; Graham and Logan, 2004; Hogan and Logan, 2004; Logan and Graham, 1998; Meyers et al., 2012; Rogers, 2003; Santesso and Tugwell, 2006; Stacey et al. 2006; Stetler, 2001), which is an important element of knowledge translation (Alberta Health Services, Alberta Mental Health Board, 2009; CIHR, 2004; Lyons, 2010). It has been reported that one reason for underutilization of knowledge or research findings is separate processes of knowledge creation and application. When the research is first conducted and the results are handed over to the end users underutilization of research findings is more likely (Birdsell et al. 2002; Choi, 2005; CIHR, 2004; Davis et al. 2003; Grunfeld et al. 2004; Jacobson et al. 2003; Johnson.

2005; Laker et al. 2013; Landry, et al. 2001; Landry et al. 2006; Oborn et al. 2010; Robson, 2002; Schryer-Roy, 2005). In spite of this important consideration, the other models of KT as mentioned above do not offer an embedded process of knowledge creation and application which is essential for a successful knowledge translation (Brownson et al., 2012; Damschroder et al. 2009; Estabrooks et al. 2006; Meyers et al., 2012; Santesso and Tugwell, 2006; Stacey et al. 2006; Sudsawad, 2007).

On the other hand the KTA model of knowledge translation encompasses all the steps between knowledge creation and its application (Bacsu and Smith, 2011; Graham et al. 2006; Lyons, 2010; NCCMT, 2010). A description of the KTA model states that:

> Further development of the OMRU by the original authors resulted in a knowledge-to-action (KTA) conceptual framework that integrates both the creation and application of knowledge to influence change in health practice settings. The more explicit framework, KTA, added value to the 'applying knowledge to generate action' framework … the transparency and fluidity of the translation process between knowledge creation and action (Campbell, 2010, p.66).

Further reasons that make the KTA model a comprehensive design include its emphasis on involving users of the product in the KT process, on exchange of knowledge and on assessment of the needs of intended user groups for the entire knowledge translation process (Graham et al. 2006; Lyons, 2010; NCCMT, 2010; Rycroft-Malone et al. 2011; Sudsawad, 2007) which are the other essential components of the knowledge translation process (Davis, 2006; Davis et al. 2003; Davis and Nutley, 2008; Davison,

2009; Green and Seifert, 2005; Jacobson et al. 2003; Lyon, 2010; NCDDR, US, 2005; Nutley et al. 2007; Pablos-Mendez and Shademani, 2006). It is reported that underutilization of the knowledge product is likely when users are not fully aware of its potential, the knowledge does not comply with the demands of the users or research is conducted first and the results handed over to the end users (Birdsell et al. 2002; Choi, 2005; CIHR, 2004; Davis et al. 2003; Grunfeld et al. 2004; Jacobson et al. 2003; Johnson. 2005; Landry, et al. 2001; Landry et al. 2006; Oborn et al. 2010; Robson, 2002; Schryer-Roy, 2005). Therefore, to increase the likelihood of a knowledge product being used, it is crucial to include users of the product and other relevant stakeholders in the process of knowledge creation and implementation (Dobbins, et al. 2002; Graham et al. 2006; Johnson. 2005; King et al. 1998; Laker et al. 2013; Lyons, 2010; NIDRR, US, 2005; NCDDR, US, 2005; Nutley, et al. 2003; Oborn et al. 2010; Stevens, et al. 2014).

Some of the other models discussed in this chapter ignore the important considerations of the KT process which are addressed in the KTA model. For example, the Stetler Model of Research Utilization and Rogers' Diffusion of Innovation theory do not promote the exchange of knowledge and involvement of the users of the product in the entire process (Bick and Graham, 2010; Davis and Nutley, 2008; Nutley et al. 2007; Walters et al. 2004). Rogers' theory has also been criticised for its passive spread of information (Alberta Health Services, Alberta Mental Health Board, 2009; Greenhalgh et al. 2004; NCDDR, US, 2005) and its one-way movement of information from producer or sender to potential users or receivers (Wiggins

et al. 2013; Zarinpoush et al. 2007). Such strategies were proven to be ineffective in encouraging the adoption and implementation of the knowledge products (Landry, et al. 2001; Macaulay et al. 2007 Minkler, 2000; Schryer-Roy, 2005).

Another reason for considering the KTA model appropriate for the present study was its clear framework. Crotty (1998), while talking about any meaningful research design for social science research, indicated that it should be a scaffold. He (1998, p.2) added that 'its aim should be to provide the researcher with ... direction as they go on to do their own building; that is, as they move towards understanding and expounding the research process after their own fashion in forms that suit their particular research purposes'. As Crotty said, the research design should help the researcher to construct their own knowledge, and provide them with a framework to follow.

Lack of conceptual clarity, specificity and transparency are limitations of some of the models discussed above including PARIHS (Sudsawad, 2007). A concern about Understanding-User-Context-Framework and the PARIHS model is that they do not provide a clear framework to follow with defined steps to achieve a successful knowledge translation (Helfrich et al., 2010; Stetler et al. 2011; Sudsawad, 2007). In addition, PARIHS and the Stetler Model are criticised for their complexity (Helfrich et al., 2010; Rempher, 2006; Stetler et al. 2011). Sudsawad (2007, p.10) argued that more demonstration is needed of how these models could be applied in an actual practice environment.

Conversely the KTA model not only covers the elements of knowledge creation, exchange, dissemination and application, but also provides a defined and clear framework to follow (Graham et al. 2006; National Collaborating Centre for Methods and Tools, Canada, 2010). As the present study intended to explore an effective way of providing appropriate information to parents of children with ASD in the context of Pakistan, by considering the development of support material as well as their implementation, KTA seemed a valid choice. KTA provides a structured system to follow, starting from identifying the problem, moving towards finding a solution, considering the local context and tailoring the intervention according to that context, and ending with intervention implementation and evaluation.

The US National Center for the Dissemination of Disability Research (2007, p.3) reports that 'knowledge to action is an organic process with defined steps'. Campbell (2010) stated that KTA has an explicit and transparent framework to follow. NCDDR, US (2007, p.5) further reported that they 'have found this conceptualization of the knowledge to action process to be a helpful and comprehensible tool for illustrating and explaining what we mean by KT to all of our stakeholders'. Therefore, due to its comprehensiveness and its defined steps to follow, it was preferred over other models for the present study.

3.3.7.6. Relevance of the Knowledge-to-Action model for developing countries

The relevance of KTA and OMRU for developing countries has also been reported. Santesso et al. (2006, p.87) stated that 'studies in developing countries, although few, illustrate that the OMRU approach may be a valid method of tackling the challenges of KT strategies to improve health care in developing countries'. Although published research about suitable research methods for developing countries was scarce (Elsabbagh et al. 2012; Sharan and Saxena, 2006; WHO, 2004), a few studies conducted in developing countries on knowledge translation may indicate the relevance of KTA and OMRU in such settings (Santesso et al. 2006).

A shortage of health and education professionals, dysfunctional health systems, limited financial resources and many barriers to knowledge translation have been reported for developing countries (Action for Autism, India, 2008; CIA, US, 2013; Elsabbagh et al. 2012; Imran et al. 2009; Majdzadeh et al. 2008; Malhotra and Vikas, 2005; Samadi, 2011; Sharan, 2008; Sharan and Malhotra, 2007; Syed et al. 2007; Tareen et al. 2008; WHO, 2005). A planned knowledge translation initiative that takes into account possible barriers, needs of target audiences, practice environment, etc. becomes essential to avoid wasting the limited resources available (Garner et al. 2004; Haines et al. 2004; Santesso et al. 2006; Siddiqi et al. 2005; Thamlikitkul, 2006; WHO, 2006).

3.3.7.7. Review of studies in which the Knowledge-to-Action model was employed

The National Institute for Health Research Collaboration for Leadership in Applied Health Research and Care for South Yorkshire (NIHR CLAHRC, SY) has used the KTA model for a variety of purposes and at different stages of their knowledge translation projects (Ilott et al. 2013; Laker et al. 2013). In a casebook, a toolkit (Ilott et al. 2011) and a series of reports on their successful use of the KTA model, they have shared experiences that can be useful for researchers embarking on projects designed to implement best evidence to improve service delivery, enhance clinical practice or introduce innovations into health or social care (Laker et al. 2013). Ilott et al. (2013, p.2) stated that KTA is a multi-dimensional and wide ranging model that offers 'a comprehensive way of examining the messy complexity of change in the National Health Service (NHS)'. They (2013) further added that the KTA model 'includes knowledge creation; mirrors the plan, do, study, act (PDSA) cycles; and includes adapting knowledge to the local context'.

Ilott et al. (2013, p.3) reported that the KTA model shaped NIHR's projects in Sheffield about enhancing oral nutrition for patients at risk of malnutrition. In addition, KTA has been used in Rotherham to facilitate the implementation of the National Institute for Health and Care Excellence (NICE) quality standards for preventing hospital acquired venous thromboembolism (VTE) (Ilott et al. 2013).

The US National Center for the Dissemination of Disability Research (2007) reported that the KTA model employed in several programmes of the

Canadian Institutes of Health Research is assessed continually regarding its impact. Ilott et al. (2011) reported that ‘since 2006, the Canadian Institute of Health Research (CIHR) have produced four casebooks. Each one showcases a number of examples of transferring knowledge into practice, highlighting the benefits for patients and the service from successful knowledge translation’. In CIHR’s Knowledge to Action: Knowledge Translation casebooks of 2008 and 2010, they have also shared a number of important lessons about successful knowledge translation, such as: the people who will use the results of the research should be involved throughout the research process, starting with helping to identify the problem; all potential stakeholders should be considered; the knowledge or research findings should be customized for specific audience(s) and should be crafted so as to have resonance with them.

In a research project, Campbell (2010) also used KTA, OMRU and Participatory Action Research (PAR) to generate a rural community’s knowledge of their children’s health, and discovered that these three models share certain commonalities. Campbell (2010) reported that they found KTA and OMRU as very useful knowledge translation models. Brouwers, et al. (2011) have also used the knowledge to action process in a project about KT for cancer control in Canada. In addition, the Saskatchewan Population Health and Evaluation Research Unit (SPHERU) of the Universities of Saskatchewan and Regina also developed a casebook on knowledge translation. Tetroe and Graham indicated that all phases in the action cycle of the KTA model have been illustrated clearly by different stories in the

SPHERU KT casebook: identifying the problem; adapting knowledge to the local context; assessing the barriers and supports to knowledge use; selecting, tailoring and implementing interventions; monitoring knowledge use; evaluating outcomes; and sustaining knowledge use (Bacsu and Smith, 2011, p.3).

3.3.7.8. Review of studies in which steps or process similar to the Knowledge to Action model were employed

Though the steps of KTA were designed carefully after an intensive theory analysis of all the major planned action theories, and were tested as well (Graham et al. 2006; NCDDR, US, 2007), review of some studies comprising any element of KT in the field of autism was also conducted to find out whether there was a common pattern of the procedures or steps followed by researchers using some model other than KTA. It was noted that these studies employed procedures or steps similar to KTA. These studies are summarised below.

In a study by Chandler et al. (of the Early Years Diagnostic Centre, Nottingham, UK, 2002), action research was employed. An intervention package for children with autism was developed, implemented and evaluated in their study. The procedure used in the study included home visits comprising discussion with parents of children with autism which was likely to serve as the baseline for intervention and also to identify objectives for the intervention. The process of developing the intervention package was not mentioned in the research paper; however, it threw light on the implementation of it. The evaluation was also a part of the study which was

carried out by using semi-structured interviews. While talking about the design, Chandler et al. (2002, p.47) briefed that the study 'employed an action research design, which essentially is responsive to participants, thus developing a user-friendly model of service'.

In another study by Whitaker (Leicestershire County Council, UK, 2002), evaluation research was used to get feedback on a Local Education Authority's (LEA) project to provide support to the families of pre-school children with autism. The overall project included a needs assessment, discussion to develop a package, and the implementation and evaluation of it. The National Autistic Society's (NAS) EarlyBird Programme was used as part of the support project for Leicestershire, however, it was 'embeded … in the context of an ongoing home visiting service, which was also available to those parents who did not participate in the workshops' (p.416). The research paper by Whitakar (2002) described briefly the methodology used in the project with a detailed description of the evaluation part of the project which was done by conducting interviews with the parents of children with ASD.

'The keyhole early intervention project in Autistic Spectrum Disorder' (2003) by PAPA (Parents and Professionals & Autism) the Northern Ireland autism charity, also employed a similar design. The extended research project funded by Department of Health, Social Services and Public Safety, Northern Ireland, aimed to 'design, develop and implement a holistic approach to interventions with families who had preschool children aged between two

and four years' (p.2). The procedure comprised a literature review and consultations with a range of professionals throughout Northern Ireland; assessment of the needs of pre-school children with autism and their parents; development and evaluation of a home-based intervention programme; enhanced provision for children with autism (pre-school provision through training of staff).

Kroeger et al. (2007) (of Xavier University and Cincinnati Children's Hospital Medical Center, USA) also described the process of implementation and evaluation of an intervention programme for young children with autism used in their study. However, the process of the development of that intervention was not described in the research paper.

In two evaluation reports on the Western Area Support Project (WASP) on early intervention with families who had a child with autistic spectrum disorders (ASD) (March 2006 and December 2006) by the University of Ulster and Autism NI (PAPA) funded by the Children Fund, Northern Ireland, different phases of evaluation were described. Out of many phases employed in the whole project (development, implementation and evaluation of early intervention programme), some include: partnerships with community, needs assessment, implementation and monitoring services.

Another early intervention programme 'parent education programs' for children with autism by Moes and Frea, (University of California, 2002) comprised different phases. The design included baseline (information by

visiting parents of children with autism), parental involvement in intervention development, implementation of intervention and follow-up.

Shields (NAS EarlyBird Centre, UK, 2001) described the areas focused on in the NAS EarlyBird programme, an autism-specific parent information or training package, were the implementation strategies used in the intervention and the monitoring and evaluation process ‘to demonstrate the effectiveness of that model of intervention’ (p.53).

In contrast to the studies mentioned above, a few studies focused only on one or two aspects of knowledge translation. Some of these focused only on the needs assessment or collection of baseline information which may be useful for material development, while some of them indicated the process of evaluating an intervention. These studies could be part of a large project with multiple phases of baseline information, knowledge creation, and its implementation and evaluation, or could be independent projects with one particular area of inquiry. They include a study by Fujiwara et al. (2011, of the National Institute of Public Health and National Center for Child Health and Development, Japan) which focused on identifying the concerns of parents of children with autism. The survey method was used to collect data and a questionnaire was disseminated to parents who visited one of the 16 leading hospitals in Japan. Another study by the University of North Carolina, USA (Alba and Bodfish, 2011, from Department of Psychiatry, Pediatrics and Developmental Disabilities) also appears to focus on the concerns of the

parents of children with ASD. This study also employed the survey method for data collection.

In a study by Cassidy et al. (2008, of Autism NI and the University of Ulster, NI) interviews were conducted to identify the impact of autism on families and the support available to children with autism and their families. The results of the study highlighted the current situation regarding the type and amount of professional support available to families of children with autism, and made recommendations for an intervention programme. It quoted (2008, p.115) that, 'Family-centred intervention and support services are required and they should be available to parents irrespective of their child having a confirmed diagnosis'.

Stahmer (2007, of University of California and Rady Children's Hospital and Health Center, USA) employed qualitative methods like Cassidy et al. (2008) using a structured telephone interview with professionals working with ASD children to identify the basic structure of community early intervention programmes for children with autism.

Concluding comments on review of studies

The review of a range of studies related to knowledge translation in healthcare fields, particularly related to autism, were summarised above to validate the researcher's choice of the KTA model for the present study. Although some of the studies used questionnaires to collect data, some employed face-to-face interviews while others used telephone interviews with

parents or professionals, and some preferred home visits to collect relevant data depending on the nature of the data required. But, the major steps were similar in all these studies which were: need assessment or collection of baseline data; development of knowledge products; implementation; and evaluation. KTA not only employs all these steps, but also include many other important steps which are considered useful for a successful knowledge transtional. Thus, the KTA model of knowledge translation was selected for the present study.

3.4. Conclusion

This chapter presented the literature review on research design which was conducted to identify a design suitable for the present study. On the basis of the literature review, it was noticed that the KTA model of knowledge translation would be a suitable design for the proposed study.

As the present study intended to examine the most appropriate method of KT for parents of children with ASD in the context of Pakistan, a suitable research design would be one which has been used in other healthcare fields, has some relevance to the context of developing countries, indicates the procedure of transferring information to an audience in an effective way, and provides guidelines on identifying what is appropriate for that audience. The KTA model of knowledge translation combines all these factors.

KTA fits the purpose of the present study as such design leads to effective knowledge transfer strategies. The KTA model not only allows for knowledge

creation e.g. provides guidelines to identify, review, select and tailor information according to the needs of a target group, but also details the procedure for implementing the intervention e.g. devises methods of transferring information to the target audience in an effective way that promotes knowledge use. In other words, it provides a proper framework to follow, starting with identification of the problem, moving towards finding a solution, and ending with intervention, implementation and evaluation. Therefore, the framework of this study was built on the KTA model of knowledge translation which is discussed in the following chapter.

CHAPTER 4: RESEARCH METHODOLOGY

4.1. Introduction

This chapter outlines the methods and procedures carried out in the study. It includes research design, sampling procedure, data collection instruments, ethical considerations and the validity and reliability of the research instruments.

The layout of the chapter comprises:

4.2. Research design and the outline of the research stages

4.3. Sampling procedure

4.4. Research tools

4.5. Ethics

4.6. Issues of validity and reliability

4.7. Conclusion.

4.2. Research design and outline of the stages

4.2.1. Introduction

This section summarises how the study was developed and processed. Reasons for selecting KTA model for the study are provided in chapter 3. This section provides a brief account of the process employed in the study and includes a description of the phases combined with a justification for each step.

4.2.2. Process employed in the present study

Crotty (1998, p.2) indicated that research design provides direction and guidelines on which researchers can conduct research in their 'own forms that suit their particular research purposes'. Ilott et al. (2013) suggested that research models should be applied flexibly to knowledge translation projects. They (2013, p.3) stated that the conceptual framework should be used 'as a tool, not a rule, so it remains 'fit for purpose''. The study encompassed several phases as transferring useful information that addresses effectively the needs of a target group requires an extensive process to follow (see chapter 3).

The study comprised the following phases:

Phase 1: Identifying the problem that needs addressing

Phase 2: Identifying the direction in which the study might evolve

Phase 3: Modifying and finalizing the research proposal

Phase 4: Identifying the appropriate methods of knowledge translation for parents of children with ASD in the context of Pakistan

Phase 5: Implementing, monitoring and evaluating parent information and the guidance pack, and sustaining its use

The first three phases were about identifying the direction in which the study might evolve – scoping the study, modifying and finalizing the research proposal.

Phase 4 constituted the main bulk of the present study. It took into account four phases of the KTA model's action cycle and three phases of the knowledge creation funnel. It comprised assessment of the setting e.g. the needs of target audiences and local context, and development of the material. The rationale for combining these phases of the KTA model into one phase is the relevance of these phases to each other (see section 4.2.2.4 below).

Phase 5 comprised implementation and evaluation of the developed material.

4.2.2.1. Phase 1: Identifying the problem to be addressed

The first step in this planned action theory comprised the identification of the problem that needed to be addressed (CIHR, 2014, Sudsawad, 2007). Graham et al. (2006, p.20) stated that 'the first step can often involve a group or individual identifying that there is a problem or issue that deserves attention'.

The problem of the unavailability of any guide, support or information pack for parents was identified by the parents of ASD children living in Pakistan.

At the time of the study, a parent group or organisation, the Pakistan Autism Meet-up Group (PAMG) was working at national level to support children and their families. On investigation, via internet searches and following discussions with a selection of parents and professionals on the forum of

PAMG, it was found that apart from this group there was no other organisation working at national level to support children with ASD and their families in Pakistan. This group, formed by parents, raised awareness of the lack of resources.

From discussions on the forum it was found that support services for parents of children with ASD were limited in Pakistan and families were reporting feelings of stress and frustration due to the lack of formal guidance or training to support their children.

The problem was further explored and verified in phase 2.

4.2.2.2. Phase 2: Identifying the direction in which the study might evolve

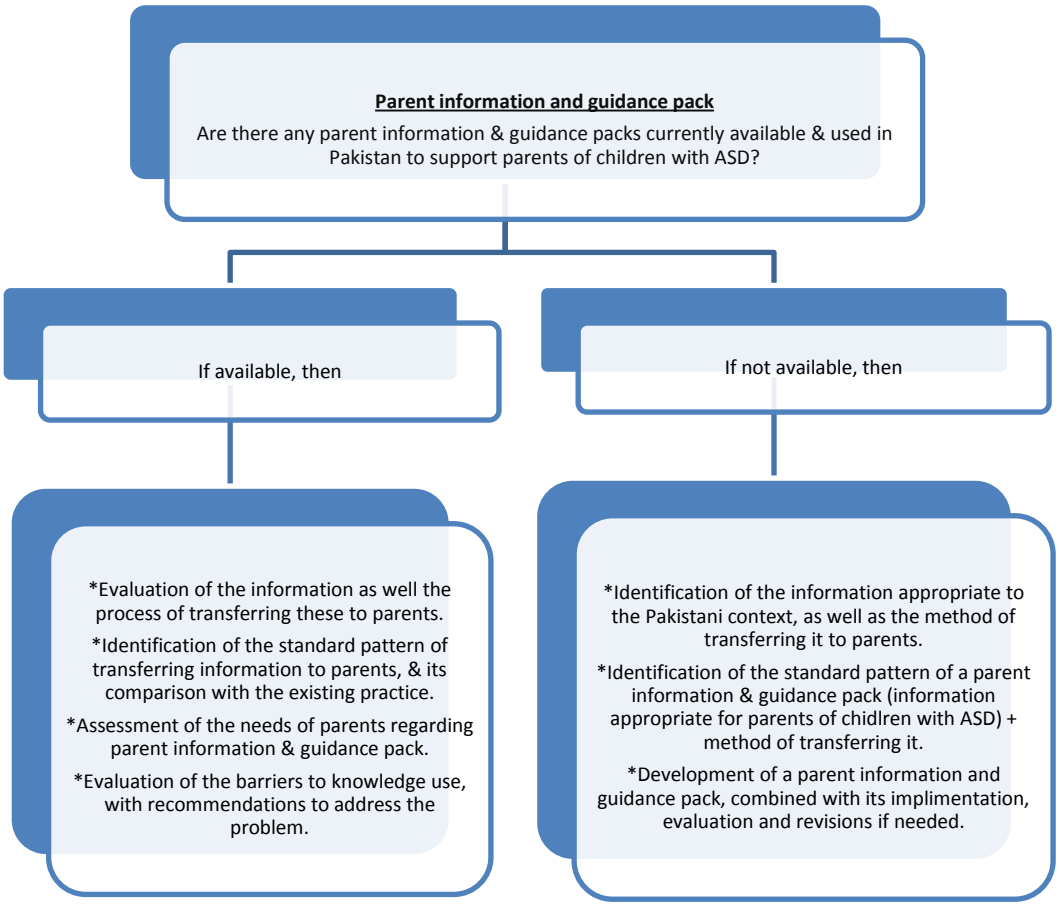
The second step of the knowledge translation process of the KTA model involves identifying and reviewing the knowledge that may address the problem identified by a group of people in the first step of KTA. This may refer to the identification of one of two situations. One may relate to identification of the system's needs to determine the type of new knowledge required, such as a health problem arising in society which may lead to the development of new knowledge or medical intervention, thus generating and translating new knowledge (Graham et al. 2006; Robert Parent, 2011).

The other may relate to the identification of the knowledge-to-action gap, which may mean that some knowledge e.g. a practice guideline, is available but is not used properly or that there is a gap between current and more

desirable knowledge, skills, attitudes, behaviours and outcomes (Graham et al. 2006; Kitson and Straus, 2011).

For the present study, phase 2 referred to the identification of any parent information and guidance pack currently available in Pakistan to identify the direction in which the study might proceed further (see Figure 4A).

Figure 4A: Identification of the direction in which the study might evolve



The figure above provides an initial framework for the proposed study showing the different dimensions of the problem on which the study might have evolved; the outcome of this stage was likely to identify the direction for the present study in one of two ways:

a. Presence of a parent information and guidance pack

   In the case of availability or usage of any parent information and guidance packs a plan was prepared to evaluate and modify what was currently available if needed. Additional information might also have been sought to identify the knowledge-to-practice gap, and consequent recommendations made to fill that gap and address the problem of underutilization of available resources.

b) Absence of a parent information and guidance pack

   In the case of unavailability of any parent information and guidance pack, preparation of an alternative plan for the study which might comprise the identification of the information appropriate to the Pakistani context, as well as the appropriate method of transferring this to parents in the form of a suitable parent information and guidance pack.

The following steps were taken to gather baseline data to identify current provision for children who may have ASD and their families; and to determine if any parent information and guidance packs were available and used in Pakistan to support the children and their families. The sample for this part of the study was selected using the technique of convenience sampling (see section 4.3):

i. A literature review was undertaken to discover the current provision for parents of children with ASD living in Pakistan.

ii. Discussion was also carried out with a sample of parents and professionals on the PAMG forum to identify some of the potential

problems they considered needed to be addressed. A new discussion thread was started by the researcher to scope the provisions for children with ASD and their families in Pakistan. Nine parents and three professionals participated in the discussion.

iii. A semi-structured interview with two professionals, one organiser and one school principal, was also undertaken to gain further views.

Following the forum discussion with a sample of parents and professionals, a semi-structured interview with one school principal and one of the organisers of the group was arranged, mainly consisting of open-ended questions. The discussion and interviews focused on information relating to the current situation of support services provided to parents of children with ASD in Pakistan, the need for and format of any information and guidance pack if required by the parents. In addition to this type of data, the interview, focused on collecting information on the accessibility of both the parents and the professionals working with them, for administration of research tools, dissemination of the information and guidance package if developed, and the availability of financial or administrative support which might be required during the research project.

The results of this phase revealed possible barriers to knowledge translation for the target group. These were financial constraints, limited resources, a limited number of trained health or educational professionals, limited understanding of ASD among parents and professionals, limited awareness of ASD among the community and a structural barrier. As ASD is an

emerging field in Pakistan, limited resources and awareness of ASD among government officials might pose challenges in organising any training for parents at national level.

The results of the literature review, discussion and interview also revealed the following facts:

- There was no formal guidance or source of information for parents of children with ASD, including any parent information and guidance pack.
- Due to the lack of provision and formal guidance or training to support their children, parents reported feelings of stress and helplessness.
- At the time of starting this study there were only a few autism units or schools for children with ASD in Pakistan which were located in two or threeof the larger cities and were non-governmental. The exact number of autism units was not identified due to the lack of any available record listing the facilities for such children.
- The diagnosis facilities were reported as very limited, and made available only in two provincial capitals, Lahore and Karachi.
- Parents had to visit a large number of professionals for several years to obtain a diagnosis that matched the child's symptoms.

4.2.2.3. Phase 3: Modifying and finalizing the research proposal

The research proposal was finalized on the basis of the results of the first two phases. It was found that there were no parent information and guidance packs currently available in Pakistan for parents of children with ASD. The

project then followed the second arm of the study framework outlined previously in Figure 4A, and aimed to explore the most appropriate method of knowledge translation in this context.

4.2.2.4. Phase 4: Identifying appropriate methods of knowledge translation for parents of children with ASD in Pakistan

Phase 4 of the present study took into account the four phases of the KTA model's action cycle (phases 2–5) and three phases of the knowledge creation funnel. As previously discussed (see section 3.3.7.3), 'there is constant movement and interaction between the knowledge creation funnel, shown in the centre of the diagram and the surrounding action cycle' (Ilott et al. 2013. p.2). In addition, phases of the KTA model can occur simultaneously, can influence each other, and the boundaries between phases are fluid and permeable (CIHR, 2014; Graham et al. 2006; Sudsawad, 2007).

The rationale for combining all of these into one phase is the dependence upon and relevance of them to each other. The phases of the action cycle and knowledge creation funnel are about assessing the needs of target audiences and the local context, then developing and tailoring a knowledge product suitable to identified needs and local context.

This phase of the study was further sub-divided into two stages. Stage one referred to collection of necessary data about the needs of the target audience and the local context, and stage two referred to the development of material on the basis of data collected.

4.2.2.4.1. Phase 4 - Step 1: Collection and identification of baseline data required for material development and implementation

Estabrooks et al. (2006, p.25) indicated that, 'Healthcare environments are complex, and assessing the setting prior to selecting a theory should be the first step in knowledge-translation initiatives. Finding a fit between setting (context) and theory is important for knowledge-translation initiatives to succeed'.

As the present study intended to explore the appropriate methods of knowledge translation for parents of children with ASD, assessing the setting (needs of target audiences and the practice environment), as well as theory (knowledge products) were important issues to be considered at this stage (Campbell, 2010, Graham et al. 2006; Graham and Logan, 2004; NCDDR, 2007).

The three phases of the action cycle, phases 2–4, were employed here: 'identify, review and select knowledge', 'adapt knowledge to the local context' and 'assess barriers to knowledge use').

It is important to note that these three phases of the action cycle were considered on two occasions: in phase 2 at the stage of scoping the study to identify the direction in which the present study might have evolved and again in phase 4 to collect data required for material development and implementation.

Description of these phases and how these were included at this stage is presented below.

- **Identify, review, and select knowledge:** This phase of the action cycle is viewed in its broader sense and refers to scoping the study (phases 2 and 3). Once the direction of an intended study is identified, this phase then comprises identifying and reviewing the knowledge or research that might address the problem identified by a group of people in the first step of KTA (CIHR, 2012; Sudsawad, 2007).

  In other words, when translation of new knowledge is required, this phase of an action cycle includes one phase of the knowledge creation funnel, 'knowledge inquiry'.

- **Knowledge inquiry** refers to identification of the information that may be relevant to the required knowledge to some extent (Graham et al. 2006). CIHR (2014) and Graham et al. (2006, p.18) added that it constitutes 'the unmanageable multitude of primary studies or information of variable quality that is out there and that may or may not be easily accessed'.

- **Adapt knowledge to the local context and assess barriers to knowledge use:** adaptation of the knowledge for the context of use and assessment for potential barriers are important issues to be considered for a successful knowledge translation (CIHR, 2014). The assessment of potential barriers and the needs of knowledge users

may lead to the tailoring or customizing of the knowledge to overcome the identified barriers and meet the needs of the knowledge users (Graham et al., 2006; Sudsawad, 2007). Graham et al. (2006) further explained that this may include the process of assessing the needs of target audiences which could be useful in translating and adapting the knowledge to the context of end users. This may also lead to making decisions about the usefulness, and appropriateness of knowledge tools during material development to the setting and context of end users (Graham et al. 2006).

Robson (2002, p.213) also indicated that the assessment of setting or needs 'should take place before the programme is set up and organized'. If the information provided to an audience is not relevant to the needs of the target group or is not transferred in an appropriate manner, then the whole process is a waste of time and effort.

In the light of the important considerations discussed above, the first step at this stage comprised the collection and identification of baseline data required for the development or implementation of the parent information and guidance pack. Therefore, the research questions asked at this stage were:

1. What is the current provision in Pakistan for children who may have ASD and for their parents?
2. What are the current approaches to supporting parents of children with ASD in Pakistan?

3. What methods of knowledge translation are being used internationally for parents of children with ASD?
4. What is the most appropriate method of knowledge translation for parents of children with ASD in the context of Pakistan?

The research tools used for data collection in phase 4, step 1 include:

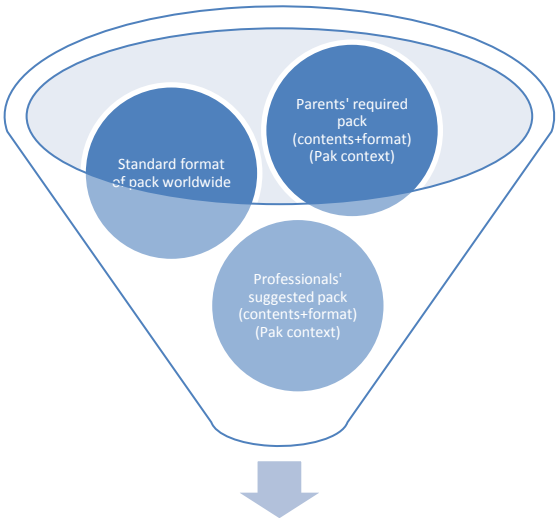
- Information gathered from autism related organisations worldwide
- A questionnaire for parents of children with ASD living in Pakistan
- Interview with parents of children with ASD living in Pakistan
- Focus group with parents of children with ASD living in Pakistan
- A questionnaire for professionals working in Pakistan with ASD children and their families
- Semi-structured interviews with professionals working in Pakistan with ASD children and their families.

The rationale for using these tools at this stage was their extensive use in assessing the needs of target audiences and practice environment in other KT projects (Alba and Bodfish, 2011; Autism NI, 2006; Cassidy et al. 2008; Fujiwara et al. 2011; Stahmer, 2007). The Canadian Institute of Health Research (2014) indicated that questionnaires, interviews, focus groups or Delphi procedure (that is to achieve consensus among a panel of experts) are appropriate tools for assessing the setting (the needs of target audiences and practice environment). Other reasons for considering these tools appropriate for this stage and for the Pakistani context, as well as detail of

how these tools were developed, is presented in section 4.4 later in this chapter, while the results will be described in chapter 5.

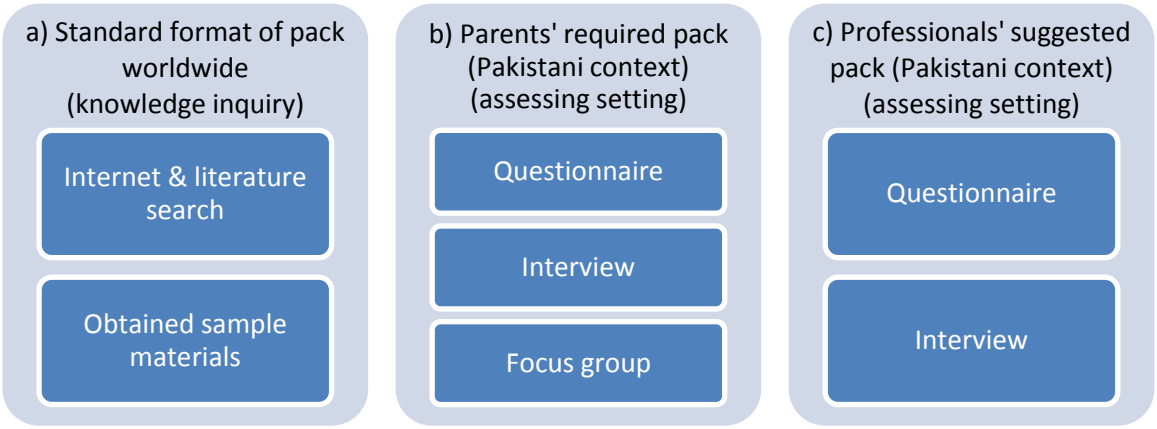
To address the research questions asked at this stage, a few steps were taken which are illustrated in the following figures:

Figure 4B: Steps involved in exploring appropriate methods of knowledge translation for parents of children with ASD in the context of Pakistan



Note: 'Pak context' in the above figure means 'Pakistani context'. The three steps discussed in Figure 4B are elaborated further in Figure 4C with description of the research tools used for each step.

Figure 4C: Description of tools used to gather data for identification of appropriate methods of knowledge translation for parents of children with ASD in the context of Pakistan.



A description of the steps taken at this stage, as shown in Figures 4B and 4C, is presented below:

a) To identify the standard format of pack worldwide and to address research questions 3 and 4, a survey of ASD-related organisations worldwide was undertaken. This included a literature review and internet search on current resources. Booklets, leaflets, and other materials designed for parents of children with autism were also reviewed. In addition, the organisations were contacted and asked to supply sample material on parent support used and or developed by them, as well as to make some suggestions on the format of a parent information and guidance pack (see chapter 6).

   This step included the ‘knowledge inquiry’, a phase of the knowledge creation funnel, and ‘identify, review, and select knowledge’, a phase of the action cycle. Details of this step will be presented in Chapter 6: Material Development.

b) To identify parents' requirement for the pack and to address research questions 1, 2 and 4, a questionnaire was developed, and interviews and a focus group was conducted with parents in the target group.

c) To identify professionals’ perspective about a parent pack, to get their suggestions, and to address research questions 1, 2 and 4, a questionnaire was developed and interviews were carried out with professionals working with ASD children and their families.

The above steps (b and c) assessed the setting, the needs of target audiences and practice environment. It included two phases of the action cycle namely, ‘adapt knowledge to the local context’ and ‘assess barriers to knowledge use’. The rationale for these steps was presented earlier in this section, while the results will be described in Chapter 5: Data Analysis.

The rationale for collecting data from the parents and professionals target groups was the importance of considering the stakeholders’ perspective in order to achieve a successful knowledge translation. To increase the relevance, adaptability and utilization of a knowledge product it is crucial to include users of the product and other relevant stakeholders in the process of knowledge creation and implementation (Dobbins, et al. 2002; Graham et al. 2006; Johnson. 2005; King et al. 1998; Laker et al. 2013; Lyons, 2010; NIDRR, US, 2005; NCDDR, US, 2005; Nutley, et al. 2003; Oborn et al. 2010; Stevens, et al. 2014).

Campbell (2010) also indicated that for effective material development and implementation, users of the product should be involved during the research process. Kitson and Straus (2011) noted that in the needs assessment process, the stakeholder’s (e.g. the population, provider organisations or healthcare providers, etc.) perspective must be considered. While talking about the classification of needs, they further added that the needs can be ‘felt needs’ (what people say they need), ‘expressed needs’ (expressed through action) or ‘normative needs’ (defined by experts). Although, it is not

essential to cover all of these in the needs assessment process, for the present study two questionnaires were designed:

1. The first questionnaire was interviews with parents and a focus group with parents to include the felt needs of the target audience. It was designed to obtain the parents' opinion about what they think they need.
2. The second questionnaire was designed for professionals working with the target group to gauge their opinion of what parents may need or what would work in the context of Pakistan. On the basis of their experience professionals not only gave their opinion about what should be given to parents, but also shared a few expressed concerns and needs of parents.

In addition, experts worldwide have developed practice guidelines and materials for parents on the basis of their consideration of what parents of children with autism may need. Therefore to consider the normative needs, booklets, leaflets, and materials designed for parents of children with autism were also reviewed (see Chapter 6: Material Development).

Robson (2002, p.213) also indicated a similar group of people who should be involved in the needs assessment process such as, 'likely consumers of the services or users of the programme, providers and managers or administrators'. Therefore the present study involved parents of children with ASD living in Pakistan, and the professionals working with these families (neurologists, clinical psychologists, paediatricians, speech and language

therapists, occupational therapists, teachers, a school principal and educational advisors).

4.2.2.4.2. Phase 4 - Step 2: Development of parent information and guidance pack

Once the context and needs of the user group were assessed, the next step was the development and tailoring of the knowledge product (CIHR, 2014; Graham et al. 2006).

This stage comprised one phase of the action cycle, namely 'select, tailor, implement intervention', and two phases of the knowledge creation funnel, 'knowledge syntheses' and 'knowledge tools or products'.

Description of these phases and how they were included at this stage is presented below:

- **Select, tailor, implement intervention:** this phase of the action cycle involves selecting and tailoring intervention appropriate to the context and needs of the target audiences (CIHR, 2014; Graham et al. 2006, p.20), because change is more likely to occur with more planned and focused interventions (Bero et al. 1998; Davies and Nutley, 2008; Davis et al. 2003; Graham et al. 2006; Grimshaw et al. 2004; Grimshaw et al. 2012; Grol, 2001).

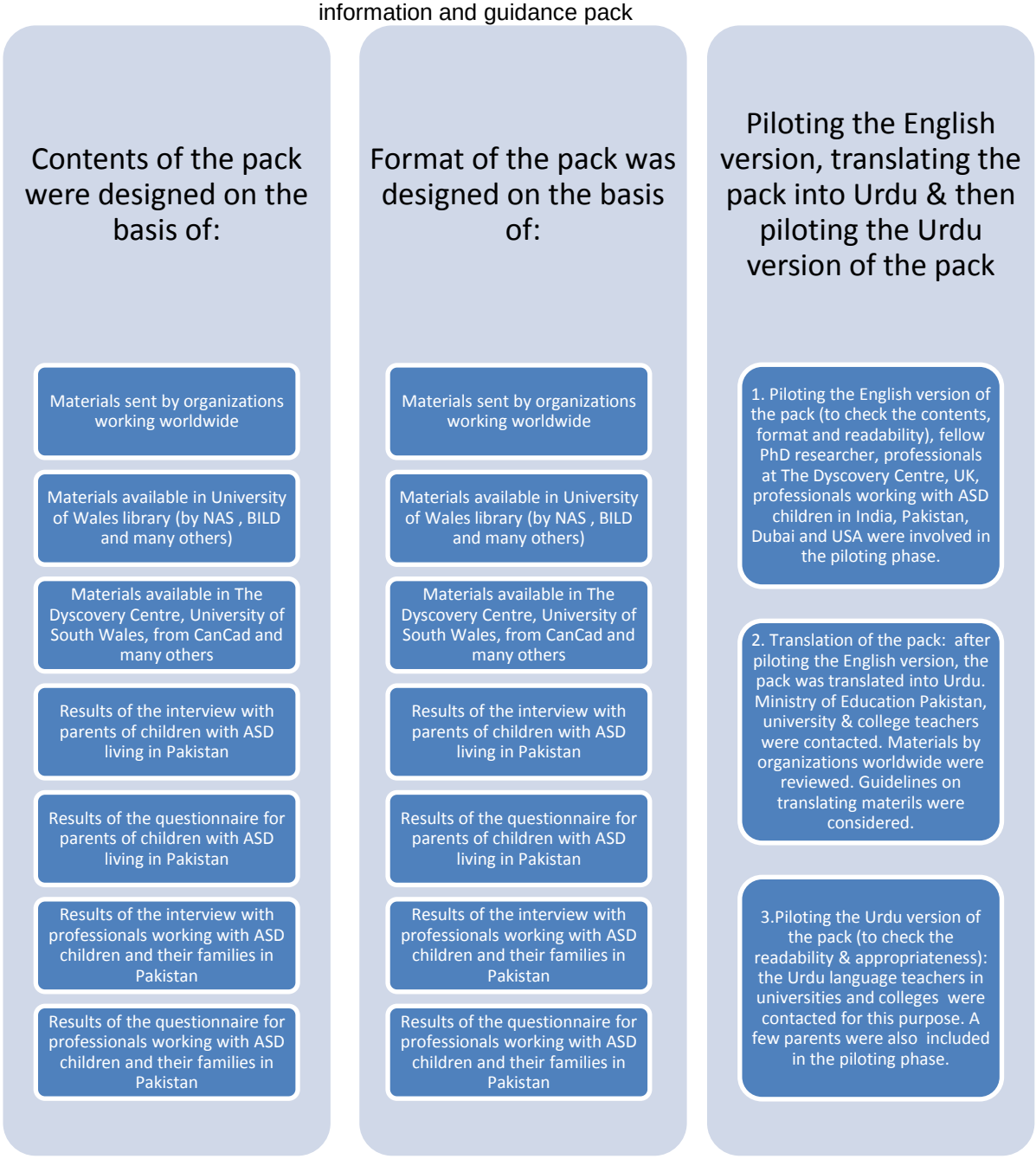
  When development of new knowledge is required this phase of the action cycle includes two phases of the knowledge creation funnel, 'knowledge syntheses' and 'knowledge tools or products'.

- **Knowledge synthesis** refers to the aggregation of existing knowledge (CIHR, 2014). This may mean evaluating, blending and reproducing the information for the purpose of making it more useful and relevant for the target audience. Graham et al. (2006, p.19) added that ‘generic knowledge is seldom taken directly off the shelf and applied without some sort of vetting or tailoring to the local context’.

- **Knowledge tools or products** refers to the final product that presents knowledge in a clear, concise and user-friendly format (CIHR, 2014). Examples include care pathways, practice guidelines and knowledge products that meet the needs of the target audience (Graham et al. 2006).

The three phases discussed above concern the development of the knowledge product and tailoring it to make it more useful and relevant for stakeholders. Steps taken at this stage are illustrated in the figure below.

Figure 4D: Steps involved in the development phase (phase 4, step 2) of the parent information and guidance pack



As discussed earlier, results of data gathered in phase 4, step 1 (presented in Chapter 5) identified the required format as well as the contents for parent information and guidance pack suitable for a Pakistani context. On the basis of the data gathered, the parent information and guidance pack was developed at this stage by working with a range of stakeholders. Once the

parent pack was developed and piloted, it was translated into Urdu and piloted again. Although an Urdu booklet was appropriate for a Pakistani context as suggested by the parents and professionals target groups, the prototype was first developed in English. The rationale for using English in the development stage was to obtain feedback from experts in a developed country, the UK, due to their expertise in the field of ASD, and for feedback in the developing countries, India and Dubai, to gain a cultural context as well. After piloting, modifying and finalizing the English version, it was translated into Urdu working with a range of stakeholders to make it fit for the target audience (see Chapter 6).

The issues considered during the process included the actual content of the parent information and guidance pack, the format of the pack and issues concerning design, length, content, use of medical terms and wider terminology, fitness of purpose, readability in English, and then its translation into Urdu and associated challenges.

4.2.2.5. Phase 5: Implementing, monitoring and evaluating parent information and guidance pack, and sustaining its use

Once the parent information and guidance pack had been developed, the next stage comprised implementing the parent pack, monitoring its use, evaluating the pack, and planning for its sustainability. This stage of the study satisfied four phases of the KTA model's action cycle (phases 5–8). As discussed earlier, phases can occur simultaneously and can influence each other (CIHR, 2014; Graham et al. 2006; Sudsawad, 2007). The rationale for combining these into one phase is their relevance to each other.

It is important to note that, as seen in phases 2-4, phase 5 of the action cycle was considered twice. Initially, at the stage of material development (phase 4, step 2), then at this stage to implement the parent pack developed as a result of the study.

Description of these phases and how they were included at this stage is presented below:

- **Select, tailor, implement intervention:** as discussed previously, this phase of the action cycle is viewed in its broader sense and refers to selecting and tailoring intervention to the context and needs of target audiences (phase 4, step 2).

  Once the knowledge products are customized to the context and audience, this phase of the action cycle comprises disseminating or executing the knowledge tools (Graham et al. 2006).

- **Monitor knowledge use:** monitoring knowledge use is necessary to determine how and to what extent information is disseminated throughout the intended audience (CIHR, 2014; Graham et al. 2006; Sudsawad, 2007).

- **Evaluate outcomes:** evaluating the effectiveness of the material developed is evident in healthcare fields (Campbell, 2010; Davison, 2009; Grimshaw et al. 2006; Santesso and Tugwell, 2006). Evaluation

is an essential component of the KTA model as it indicates whether the knowledge introduced as a result of the study made any difference, and was successful and worth using (Graham et al. 2006; Sudsawad, 2007).

- **Sustain knowledge use:** the final phase of the action cycle is about sustaining the use of knowledge (Sudsawad, 2007). Graham et al. (2006, p.21) reported that 'interest in sustainability of knowledge use is relatively recent, and so there has not been much research into this important aspect of the KTA process'.

In the light of the important considerations discussed above, the first step at this stage comprised dissemination of the parent information and guidance booklet designed for parents of children with ASD. The booklet was either posted to the homes or work addresses of the intended audience or was distributed among a few professionals and parents of children with ASD with the help of a provincial and a national level organisation (see section 4.4).

The step associated with dissemination is monitoring knowledge use and it can have different implications for different projects. For the present study it determined the extent to which the parent pack had disseminated throughout the intended audience (CIHR, 2014; Graham et al. 2006). To make sure the parent pack reached the intended audience, it was posted to their homes or place of work via registered post. As a few booklets were distributed with the help of two organisations, a sample of the intended audience was contacted

to get information about the dissemination of those booklets. It was found that 55 parent information and guidance booklets sent to the organiser of an NGO were not distributed. Therefore, more copies of the parent pack were posted to the relevant professionals directly (see section 4.4).

To address the issue of evaluation, two questionnaires were designed to evaluate the effectiveness of the parent information and guidance pack:

- A questionnaire for parents of children with ASD living in Pakistan
- A questionnaire for professionals working in Pakistan with children with ASD and their families.

These questionnaires were developed in English. Once developed, they were then piloted, translated into Urdu, piloted again, and then administered to collect the necessary data. The rationale for considering these tools appropriate for this stage and details of how they were developed is presented in section 4.4 later in this chapte and the results will be described in chapter 7.

In addition, an informal telephone interview with a sample of professionals working with ASD children and their families in Pakistan was carried out to discuss the issues of dissemination and sustainability of the guidance pack. The professionals interviewed for this stage of the study included one organiser of a provincial level NGO, one organiser of a national level NGO and one paediatrician who was head of the Paediatric Department in a government hospital. On the basis of informal discussion with these

professionals, the suggested recommendations and further plans will be presented in chapter 8.

4.3. Sampling procedure

Cohen (2000, p.100) indicated: ‘The quality of a piece of research stands or falls not only by the appropriateness of methodology and instrumentation but also by the suitability of the sampling strategy that has been adopted.’ The key elements of selecting a sample include access to the sample, and the representativeness of the sample selected (Cohen, 2000). Convenience sampling is a commonly used sampling method in behavioural science research, nursing research and in other healthcare fields due to the problem of accessibility, availability of patient groups or respondents, willingness of the respondents to participate in the study, and availability of any list of the target population (Fink, 1995; Gravetter and Forzano, 2011; Wood and Kerr, 2011).

The unavailability of any government record listing the parents of children with ASD or the professionals working with these families in Pakistan raised the problem of identification of the target population. Convenience sampling was considered the most appropriate procedure for the current study. Wood and Kerr (2011, p. 156) indicated that non-probability sampling is used when ‘no list of all members of target population is available, or availability is expected to be sequential’. Kumar (2005, pp.177–178) also supported that ‘non-probability sampling designs are used when the number of elements in a population is either unknown or cannot be individually identified’. In

addition, this is the most appropriate sampling technique given the limited time (Drew et al. 2008; Neuman, 2006), resources (Boudah, 2011; Fink, 1995; Greenfield, 2002; Welman and Kruger, 2001) and access to population (Cohen, 2007; Johnson and Christensen 2012; Kumar, 2005; Ruane, 2005; Robson, 2007).

4.3.1. Participants

The professionals identified as possible participants for the study were educational advisors (autism educators), school teachers, school principals, organisers of NGOs working to support children with autism and their families, paediatricians, neurologists, psychologists, speech and language therapists and occupational therapists. The rationale for collecting data from parents of children with ASD living in Pakistan and professionals working with them was the importance of considering the stakeholders' perspective for a successful knowledge translation (Dobbins, et al. 2002; Graham et al. 2006; Johnson. 2005; King et al. 1998; Laker et al. 2013; Lyons, 2010; NIDRR, US, 2005; NCDDR, US, 2005; Nutley, et al. 2003; Oborn et al. 2010; Stevens, et al. 2014), (see phase 4 in section 4.2).

The criterion for inclusion of a professional in this study was that they should have been working with ASD children and their families for more than one year. Professionals who had not worked with ASD children and their families for more than one year before the questionnaires were administered or interviews were held were not included in the study, the rationale being the

need for up-to-date information about the practice environment and services provided to the target group.

The criteria for inclusion of a parent in this study were that the age of their child should be between three and eleven years, and their child's diagnosis should have been made not more than three years before the questionnaires were administered or the interviews and focus group interviews were held. The rationale for excluding those whose children received an earlier diagnosis was the need for up-to-date information about the process of getting a diagnosis of ASD in Pakistan and services provided to the target group.

For the evaluation of the parent information and guidance booklet designed as a result of this study, the parents recruited in the initial phases of the study, for needs assessment and baseline information, were again invited to take part in the final phase. The exclusion criterion was not applied to them for two reasons. First, as ASD is an emerging field in Pakistan a limited number of children were diagnosed due to the limited understanding of the condition among communities and relevant professionals, (see chapters 2 and 5). Identifying and recruiting parents of ASD children was challenging even for the initial phases of the study, therefore excluding the available sample would have resulted in a fairly small sample size. Second, the suggestions and needs of parents who participated in the initial phases were considered while developing the parent information and guidance booklet, therefore it was necessary to obtain their views about the final product, and

to identify that it matched their required and suggested prototype (Mays and Pope, 1995).

4.3.2. Recruitment procedure

Two organisations were asked to help in the identification of potential participants: the Pakistan Autism Meet-up Group (PAMG) and Tanzeem Idara Bahali Mustehqeen (TIBM). PAMG was the only organisation working at national level to support families of children with ASD in Pakistan, however, the activities of this parent led organisation were limited to a discussion forum and occasional workshops or meet ups (e.g. a few parents occasionally getting together to discuss the problems of their children and see if any other parents had come across a similar situation and were aware of any solutions). TIBM was a provincial level organisation working to promote literacy in the country including adult literacy and education of children with SEN. Supporting parents of children with ASD was not a focus of TIBM, but their help was requested in identifying any professionals working with such families and any special schools from where parents of children with ASD might be contacted to ask about their willingness to participate in the study.

In addition, phone numbers or addresses of hospitals, therapy units and schools for children with ASD in major cities of the country were searched on the internet to contact the professional target group. However, there was a lack of government records listing professionals working with children with ASD in Pakistan, and so one could not ensure that contact information of all

possible participants was availableon the internet. Therefore, in order to approach as many potential participants as possible, major hospitals, therapy units or schools for children with ASD in the researcher's city and in two provincial capitals, Lahore and Karachi, were visited in person to collect contact information for the professionals working there. Health and education professionals whose information was found on the internet or collected by visits were contacted via emails, letters or phone calls to ask if they would participate in the study and help in identifying potential participants. Additionally, the members of PAMG were contacted via email, and a letter was posted to TIBM as their email address could not be found on the internet. Face-to-face meetings were also arranged with a few professionals who expressed an interest in participating in the study, but requested to discuss the project in detail or to provide contact detail of potential participants in person.

These organisations together with the health and education professionals were contacted to request their support in locating as many parents as possible of children with ASD and professionals working with these families. With the support of these organisations and health and education professionals initially around sixteen parents of children with ASD and nine professionals working with these families were identified. With their help more potential participants were located. For example, the organiser of a parent led organisation was aware of the professionals working with ASD children in their city and provided their contact details. These professionals were then informed about the project and asked if they would be willing to

take part in the study. If the professionals expressed an interest in participating, they were also asked if they knew any other professionals working in the field of ASD or parents of children with ASD. Likewise, one school principal provided the phone numbers of parents of children with ASD enrolled in her school. Those parents were then contacted to enquire about their willingness to participate in the study. Those who expressed interest were also asked if they knew any other parents of children with ASD or professionals working in the field of ASD. In this way, with limited time and resources as many parents as possible of children with ASD and professionals working with these families were approached.

For the initial phases of the study, around one hundred and fifty potential participants were identified, but for several reasons, including missing or incorrect contact information of a potential participant, six of them were not informed about the project and asked if they would be willing to participate. In six cases the researcher only got the phone number of a likely respondent and, unfortunately, the numbers for three parents of children with ASD, one educational advisor and one child psychiatrist did not exist anymore. In addition, one child psychiatrist did not respond to repeated telephone calls. As indicated by Gravetter and Forzano (2011, p.151), in convenience sampling ‘people are selected on the basis of their availability and willingness to respond’, thus those available and willing to participate were included in the study. As it was a multiple stage study, the number of people who participated differed at each phase. (see sub-sections 4.4.1.2.4, 4.4.2.1 and 4.4.3).

For the initial phases of the study the sample was selected from Lahore (the capital of Punjab Provinc, the most populous province of the country comprising 55.63% of the whole population), Karachi (the largest city of Pakistan and the capital of Sindh Province comprising 23% of the whole population) and Multan (a major city of the country) (National Public Radio, 2008; Population Census Organization, Government of Pakistan, 1998 census).

The rationale for selecting the sample from these cities was that at the time of starting this study diagnostic facilities for ASD appeared to be available only in Lahore and Karachi. There appeared to be no schools for ASDs or any therapy available except in a few major cities. Thus, professionals working in Lahore and Karachi were included in the study, plus a neurologist and a paediatrician working in Multan for the initial phases. In the case of a parents' target group, as the support services for children with ASD appeared to be available in only a few major cities of Pakistan, parents either prefer to move there or have contact with professionals working in those cities, which made it possible for the researcher to contact those parents to enquire about their willingness to participate in the study.

However, as the researcher later received links to other parents and professionals from those who participated in the initial phases of the study more parents and professionals from all the provincial capitals, as well as from the major cities of Pakistan, were contacted and recruited; these include

Lahore, Karachi, Multan, Hyderabad, Faisalabad, Islamabad, Peshawar and Quetta (Central Intelligence Agency, US, 2013; Ministry of Economic Affairs and Statistics, Government of Pakistan, 2010).

The parents and professionals who participated in the initial phases of the study, which comprised assessment of needs, etc., were again invited to take part in the final evaluation phase. In addition to those who participated throughout the study, more parents and professionals identified by those who participated in the initial phases were also informed about the project and asked if they would be willing to take part. Those who expressed an interest were recruited for the evaluation phase (for details see 4.4.1.2.4, 4.4.2.1 and 4.4.3).

4.4. Research tools

As this was a multiple-staged study different research instruments were used at different stages to collect the necessary data. These were questionnaires, interviews, delivery of a focus group and a survey of organisations working worldwide to support ASD children and their families.

4.4.1. Questionnaires

Four questionnaires were developed and administered at different times during the study; two at the beginning of the study to gather baseline data, and two at the end of the study to evaluate the effectiveness of the prepared parent information and guidance pack (Campbell, 2010; Estabrooks et al. 2006; Graham et al. 2006; Kitson and Straus, 2011; Robson, 2002).

To identify a method of transferring appropriate information suitable to a Pakistani context it was essential to select a sample from different cities to address the issue of representativeness of the sample i.e. parents of children with ASD living in different cities in Pakistan and professionals working with them. Since a questionnaire provides a more convenient way to reach a geographically dispersed population (Creswell, 2008), it was considered the most appropriate instrument for the present study.

Another major reason for choosing a questionnaire was that it could be used to describe trends in the attitudes, beliefs and opinions of a population (Creswell, 2005; Fink, 1995), and to identify the needs of a particular group (Creswell, 2005; Robson, 2002). Additionally, it 'is a widely used and useful instrument for collecting information, providing structured, often numerical data' (Cohen, 2000, p.317) to simplify analysis (Robson, 2007) and to allow for the collection of standardised data by using the same questions for all participants thus reducing the effect of the researcher on the responses (Cohen, 2007; Robson, 2007; Sarantakos, 1998).

The advantages of using the questionnaire also included attracting a dispersed sample with the minimum of resources (Cresswell, 2005; Robson, 2007; Sarantakos, 1998). It is more economical than the interview in terms of time and money (Cohen, 2007; Gay, 1996). As only one researcher was involved in the study, given the dispersed geographic location of respondents targeted, the time frame of the study and the limited financial resources of

the researcher, data collection through interviews would have been impossible. Interviews were also carried out with a sample of parents and professionals following on from the questionnaire to achieve more in-depth detail (Cresswell, 2005), but the questionnaire was used as the main tool of the study because of its cost effectiveness, and since it was presumed that, due to the busy schedule of professionals, fixing an appointment for an interview could be difficult (Berdie, 1986). A questionnaire can be administered without the presence of the researcher (Cohen, 2007) and it allows the respondents to complete it at the time and place of their choice (Berdie, 1986; Gay, 1996; Sarantakos, 1998). The limitations of this approach were that the percentage of returns is often low and a longer period of time is needed to receive the completed questionnaires (Gay, 1996; Oppenheim, 2000). The type of question asked is also an important issue to be considered (Gay, 1996). Open-ended items are good in one way as they increase the possibility of getting enriched data. The respondents freely describe their experiences, perceptions, ideas or opinions without being constrained by closed questions. Thus it not only provides the data required by the researcher, but may also increase the flavour of it by unveiling new dimensions. Conversely, if only open items are used respondents may be unwilling to write their answers for one reason or another, particularly since they may perceive this as more time consuming (Kumar, 2005). Closed questions are thought to increase the response rate as it take less time to fill in the questionnaire and they are comparatively easy to answer (Gillham, 2008). However, if only closed items are used, the questionnaire may lack coverage or authenticity (Oppenheim, 2000).

Therefore, for the present study, a mix and match approach was used depending on the needs. In places multiple choice items were used for the ease of the respondent and to increase the response rate. In other places open-ended questions were asked to get a clearer picture. A review of the related literature and similar studies was carried out before designing the questionnaires, which provided the basis for the questionnaire items. Although a standardised questionnaire suited to the particular needs of this research was not available at the time of writing, some studies on similar issues provided guidelines for the content and structure of suitable questionnaire items (Keenan et al. 2010; Lang et al. 2010; Osborne and Reed, 2008; Wiggins et al. 2006).

The questionnaires were developed for parents of children with ASD living in Pakistan and for professionals working with these families. The process involved designing the initial drafts on the basis of the literature review, distributing them among experts and professionals for their feedback, reframing the questions once feedback was received, and then distributing it again among the experts for feedback and further refinement (see Figure 4E below).

Figure 4E: Process of questionnaire development

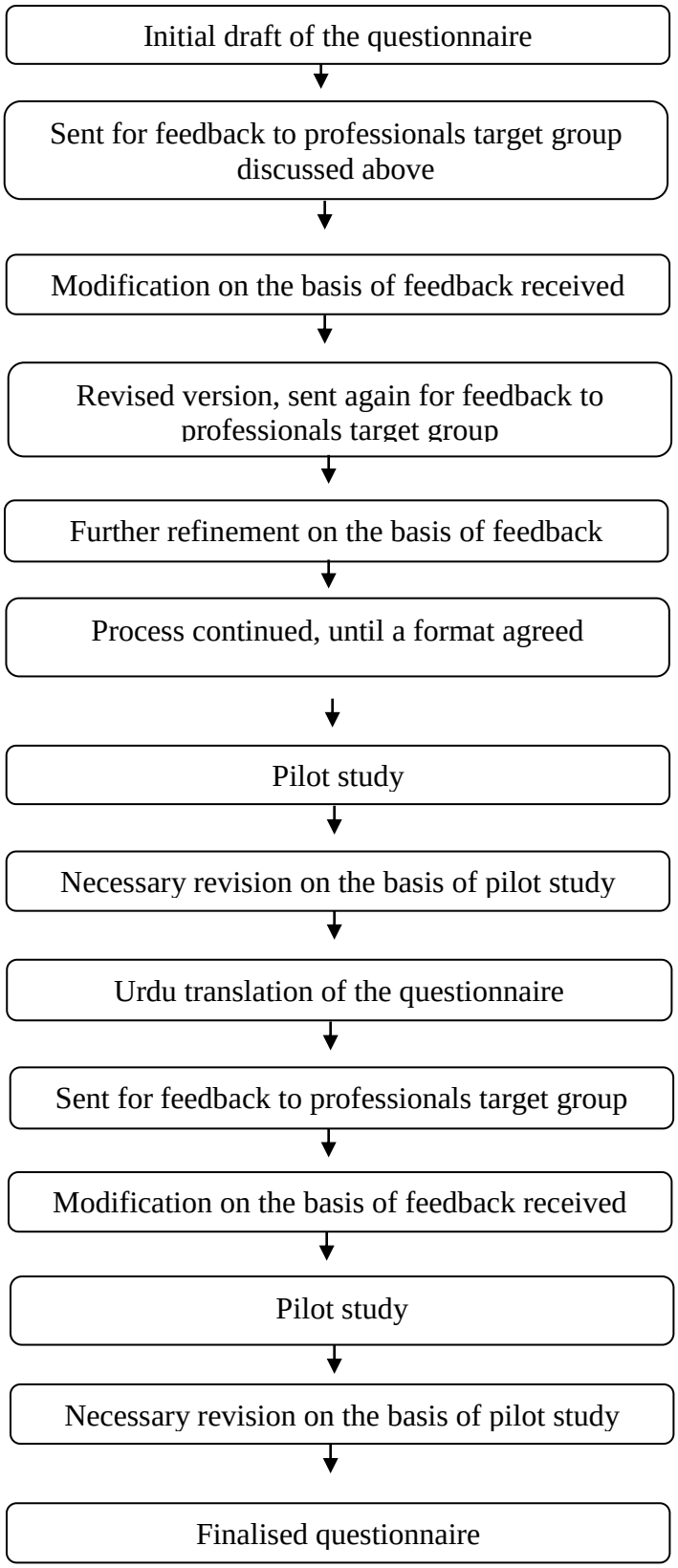
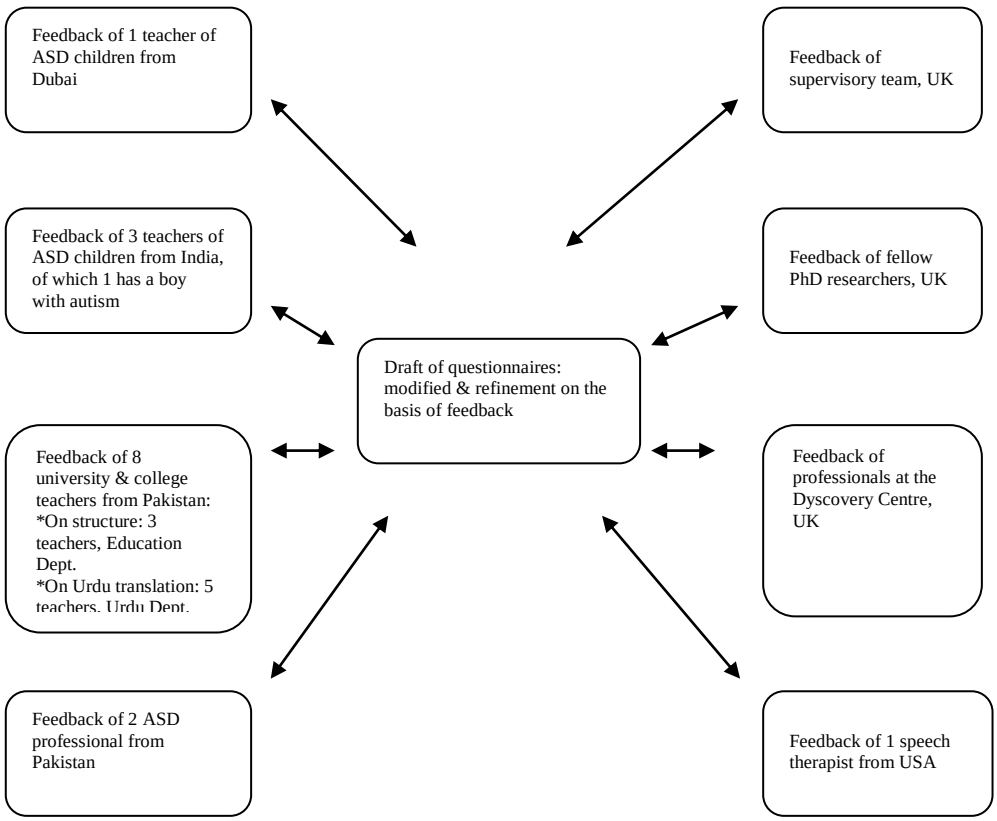


Figure 4F: Professionals involved in the questionnaire development process



Robson (2002, p.213) indicates that questions selected 'can be gleaned from a variety of sources, including the literature (if any), experts in the field and those likely to be involved in the programme in any capacity'. On the issue of making the questionnaires more relevant to the study, discussions were carried out several times between researcher and supervisors, researcher and fellow PhD students, the professionals at The Dyscovery Centre, University of South Wales; and the professionals who worked or were working with ASD children in India, Dubai, the US and Pakistan (see Figure 4F). The rationale for asking the opinion of experts in a developed country (e.g. the UK) was their expertise in the field of ASD, as well as feedback from the developing countries to gain a cultural context.

Guidance and feedback from all of these experts on the structure and questions of the questionnaires helped to make the tool more focused and relevant to the research. For example, due to the feedback on a cultural context, questions were designed according to the level of the respondents' understanding. Considering that the term 'knowledge translation' was not commonly used or understood in Pakistan by the parents', or even the professionals' target group, equivalent terms used or understood in Pakistan (e.g. format of parent information pack, methods of providing information to parents) were selected.

Likewise, the structure of the questionnaires was also tailored to the needs of target audience. For example, keeping in mind the increased workload on health professionals in developing countries due to the shortage of a trained workforce, similar questions were grouped together and presented in tables with multiple choice answers to save the time of the respondent. a similar approach was used in questionnaires with parents to increase the ease of understanding and reduce the number of questions which might otherwise have resulted in limited returns.

Needs, interests and understanding levels of participants were taken into account even when deciding the order of the questions. For example, while asking about parents' suggestions regarding methods of knowledge translation, the questions begin with the type of information they would like to

receive, move on to the language they would prefer, and end with the method they considered appropriate.

Once the questionnaires were finalized, piloting was undertaken to refine the contents, wording, length, etc. to make them appropriate for the sample being targeted (Cohen, 2007). In order to avoid the possibility that the participants may not have read the questionnaire properly or might misinterpret the questions (Creswell, 2005), a pilot study was conducted. After minor modifications identified in pilot study were made, the questionnaires were finalized.

4.4.1.2. Design and other details of each questionnaire used in the present study

4.4.1.2.1. Questionnaire for parents of children with ASD living in Pakistan

A questionnaire for parents of children with ASD living in Pakistan was developed to assess their needs regarding a parent information and guidance pack, i.e. what information would they like to receive and in what format?, to identify the support services available for children with ASD and their families in Pakistan, as well as to scope the satisfaction of parents with the support services available (see chapter 3 and section 4.2.2.4. of this chapter for the rationale for collecting this information, and Appendix-I for the questionnaire).

Design

The questionnaire was in three parts:

Section A covered the questions related to the diagnostic process of ASD in Pakistan, parents' concerns or satisfaction and comments about the process (Estabrooks et al. 2006; Graham et al. 2006).

Section B focused on the support services provided to children with ASD and their parents (Estabrooks et al. 2006; Graham et al. 2006).

Section C comprised the assessment of needs of parents regarding guidance and support services (Estabrooks et al. 2006; Graham et al. 2006; Kitson and Straus, 2011).

Robson (2002, p.213) indicated that the design for such needs assessments may comprise 'rating the importance of each' need i.e. contents of the pack, and 'current availability' combined with 'information about how needs are currently being met. (see also chapter 3 and 4.2.2.4. of this chapter.)

Length

There were 14 questions comprising rating scales, multiple choice questions and open-ended questions with space for respondents to expand them. Completion took approximately 10 to 15 minutes.

4.4.1.2.2. Questionnaire for professionals working in Pakistan with children with ASD and their families

A questionnaire for professionals was also developed focusing on the concerns reported by parents of children with ASD, and to gain suggestions from them about the most effective way of providing appropriate information to parents of children with ASD living in Pakistan (see Appendix-J).

Design

The questions were based on two themes which were ‘parents’ concerns’ and ‘format of parent support pack’ (Estabrooks et al. 2006; Graham et al. 2006; Kitson and Straus, 2011). Robson (2002, p 213) indicated that the design for such questionnaires may comprise ‘rating the importance of each’ need i.e. contents of the pack. (see also, 4.2.2.4.).

Length

There were nine questions comprising rating scales, multiple choice answers and free answers with space for respondents to expand them. Completion took approximately three to five minutes.

4.4.1.2.3. Questionnaires for parents of children with ASD living in Pakistan and professionals working with these families

To evaluate the effectiveness of the parent information and guidance booklet designed for parents of children with ASD living in Pakistan, two questionnaires were developed (one to be completed by parents of children with ASD, and one by professionals working with these families) (see Appendices K to N). As the relevance of material is likely to promote its usage and affects its sustainability (Graham et al. 2006), evaluation of the material developed as a result of the study was conducted to identify and eradicate the irrelevant or ineffective parts for the purpose of making it more useful and relevant to the target audience. This tool was used because evaluation is an essential component of any process; evaluation not only identifies the effectiveness of a product or a process, but also highlights its flaws (see 4.4.1.).

Length

There were 14 questions in the questionnaire designed for parents of children with ASD, and 13 in the questionnaire designed for professionals working with ASD children and their families. The questionnaire comprised rating scales, multiple choice questions and open-ended questions with space for respondents to expand them. Completion took approximately five to eight minutes.

4.4.1.2.4. Administration, limitations and other details of questionnaires used in the present study

Recruitment procedure and data collection

Organisations working in Pakistan to support the families of children with ASD and a sample of health and education professionals working in major cities of the country were asked to contact parents and professionals to ask if they could participate in the study (see 4.3 for further detail). For the initial phase of the study the questionnaires were either posted to those who gave consent, left at the child's school for the parents, or in some cases, handed out to the participants. Few questionnaires were completed by parents, and in some cases face-to-face completion was carried out to avoid exclusion of the parents who may have had difficulty with the necessary literacy to complete the questionnaire (Robson, 2002). As the questionnaire designed for the initial phase of the study required a lot of input from the participant including services provided for ASD children and their families, satisfaction of the parents with the services provided etc., face-to-face completion become necessary for parents with limited literacy or understanding (Robson, 2002).

54 questionnaires from professionals and 59 from parents were returned after follow-up phone calls by the researcher.

For the evaluation phase of the study, the booklet designed for parents of children with ASD was posted to those who consented along with the questionnaire and a pre-paid envelope. The questionnaires were either posted to their homes or work addresses or were distributed among a few professionals or parents with the help of a school principal, an organiser of an NGO, and a provincial level organisation. 120 questionnaires were sent out initially, out of which, 55 were sent to an organiser of an NGO who was supposed to give it them to a school principal and other professionals who work in the same hospital, but unfortunately, those 55 booklets and the questionnaires were not distributed. Five weeks later more copies were posted to the relevant professionals directly. 51 filled questionnaires were received from parents, some partially and some fully completed. 46 were received from professionals after follow-up calls and reminders, of which one was blank; one inadequately filled Urdu version of the questionnaire was also received. On the first page of inadequately filled questionnaires, all three options in the multiple choice questions were selected, while the remaining pages were left blank. Therefore 44 completed questionnaires were included in the analysis.

Study limitations

For the initial phase of the study the questionnaires were designed in English (the official language of Pakistan) at the request of the parents and

professionals contacted earlier in the development phase. The researcher was aware however that an Urdu (the national language of Pakistan) version would have been more accessible for all respondents. However, it was likely that designing the questionnaire solely in Urdu would have resulted in a small return as people might have considered the English version a more professional survey. Additionally, as the questionnaire required a lot of input from the parents, e.g. assessment of needs and practice environment, etc., which is essential for a successful knowledge transfer, participants with lower levels of literacy or understanding might even have difficulty completing the Urdu version. Therefore, for the purpose of consistency, the questionnaire was designed in one language but a face-to-face completion was arranged for such participants.

For the evaluation phase of the study, the questionnaire was produced in both English and Urdu. The rationale for translating it into Urdu was to make it accessible for the audience with low levels of literacy or understanding or for whom a face-to-face completion of the questionnaire was undertaken in initial phases of the study but limited time and resources did not allow for a repeat at this stage. Unlike the questionnaire used in the initial phase, it was brief, simple and easy to complete and did not require multi-dimensional input from the respondents (see Appendices M and N).

The English version of the questionnaire was used with the majority of the professionals and some parents as they expressed a preference. Conversely, an Urdu version was sent to those for whom a face-to-face

completion of the questionnaire was undertaken in initial phase of the study, those who requested an Urdu version, or those who had low levels of literacy or understanding.

Though the researcher was aware that providing the questionnaire to all respondents in one language would have been easier and more consistent, the needs of the respondents were considered as it was a real world research study (Robson, 2002). Thus, the questionnaire was administered in two languages to increase the response rate, and to meet the requirements of a range of respondents having different interest, literacy and understanding levels.

4.4.2. Interview

In addition to the use of questionnaires, some parents of children with ASD and the professionals working with these families were interviewed to collect additional relevant data. The interview approach was selected for data collection as Cohen et al. (2007) explained that if the interviewer does his job well (establishes rapport, asks questions in an acceptable manner, etc.), and if the respondent is sincere and well motivated, accurate data may be obtained. In addition, the interview is a flexible tool for data collection, enabling multi-sensory channels to be used (Cohen et al. 2007).

An interview was chosen in addition to the questionnaire because by asking specific questions the relevant and required information can be received (Creswell, 2005) and the responses about complex and deep issues can be

made possible (Cohen et al. 2007), increasing the likelihood of getting complete answers (Oppenheim, 2000). In addition, interviews are most suitable when little is known about the research topic, or where there is a need 'to explore the views, experiences, beliefs/or motivations of individuals on specific matters' (Gill et al. 2008, p.292; Stewart et al. 2008).

Since very limited or no information was available from any authentic sources, e.g. published papers, government records, etc., about the process of getting a diagnosis of ASD in Pakistan, parents' concerns, the facilities or support services available for ASD children and their families in Pakistan, the quality of those services and many other similar issues, interviews seemed essential to get detailed, in-depth and comprehensive data on these issues. Gill et al. (2008, p.292) said that 'interviews, are believed to provide a "deeper" understanding of social phenomena than would be obtained from purely quantitative methods, such as questionnaires'. Cohen et al. (2007) indicated that interviews allow for greater depth and enables participants to discuss their interpretations of the world in which they live, and to express how they regard situations from a personal point of view.

It is also important to note that there is a general trend in Pakistan for people to avoid answering questions which require written input from them. If the respondents are professionals, their busy schedules add to their reluctance to provide written answers. In developing countries like Pakistan where a shortage of trained workforce is reported, it is obvious that the limited number of trained health and education professionals is carry a high

workload (Malhotra and Vikas, 2005; WHO, 2005). This increases the importance of interviews in such settings. In the case of the present study, a similar response to the open-ended questions was received and most of them were left blank. Therefore, interviews were conducted to get input from parents and professionals on certain topics that needed their views.

Another reason for carrying out interviews with parents was to avoid exclusion of the opinion of parents who may have limited literacy or levels of understanding necessary to understand and respond to the questions asked in a questionnaire (Robson, 2002). As interviews provide an opportunity for correcting misunderstandings (Oppenheim, 2000) they were considered appropriate for parents with limited understanding. Cohen et al. (2007) added that the interviewer is able to answer questions concerning both the purpose of the interview and any misunderstandings experienced by the interviewee, since same questions can have different meanings for different people.

4.4.2.1. Design and other details of the interview schedule

Semi-structured interviews mainly consisting of open-ended questions (Gay, 1996), were carried out with both parents and professionals. Such questions allow the participants to best voice their experiences without being constrained by the researcher's perspectives (Creswell, 2008). Furthermore, open-ended questions provide flexibility and press for a comprehensive answer (Cohen, 2007).

Recording of interview data was also a matter of concern, as according to Cohen et al. (2007) there is the potential for massive data loss. Thus, interviews were audiotaped to yield accurate data in the case of those who consented to being recorded. For those who did not consent to an audio recording or seemed uncomfortable or constrained with a recording, the researcher simply took notes on a paper during the interview (Cresswell, 2005).

Recruitment Procedure

The parents' and professionals' target groups selected to complete the questionnaire were asked about their willingness to participate in an interview (see section 4.3). Those who gave consent were contacted in person at their place of choice. Interviews with professionals were usually conducted at their place of work, as their expressed preference. In the case of interviews with parents this was the participant's home or the hospital attended for their child's therapy. 16 professionals, 17 parents and one grandparent were interviewed for this part of the study.

Challenges faced

The distance travelled to different cities and sometimes to the work places of professionals or the homes of parents to conduct interviews with them was very expensive and time consuming. Agreeing convenient meeting times with professionals also proved problematic.

4.4.2.1.1. Interviews with parents of children with ASD living in Pakistan

Semi-structured interviews were carried out with the parents' target group. The interviews focused on support services available to parents and the needs of parents regarding an information and guidance pack, e.g. the preferred methods for receiving information and suggested contents for the pack (see Appendix-F for interview schedule).

Design

The questions for the interview were based on the same three themes used in the questionnaire for the parents (see 'Design' in 4.4.1.2.1). However, it did not restrict the participants to talk on selected themes, but gave them the chance to share any experiencse or ideas on any issue related to the provision for ASDs in Pakistan.

Length

The interview was designed to be10 to 15 minutes (approximately). However, with some parents, it took 20 to 25 minutes depending on their willingness to share more information.

4.4.2.1.2. Interviews with professionals working in Pakistan with children with ASD and their families

Semi-structured interviews were carried out with 16 professionals about the appropriate methods of providing information to parents, contents for a potential parent information pack and concerns reported by the parents to get a more representative picture of the needs of parents according to the

knowledge of each population of professionals (Creswell, 2008) (see Appendix-H for interview schedule).

Design

The questions in the interview were based on similar themes to the questionnaire for the professionals (see 'Design' in 4.4.1.2.2). The themes used in the interview were 'parents' concerns', 'appropriate methods of knowledge translation in the context of Pakistan' and 'contents for a potential parent support pack'. However, it did not restrict the participants to talk on selected themes but gave them the chance to share any experiences or ideas on any issue related to the provision for ASDs in Pakistan.

Length

Due to the busy schedule and the reluctance of some professionals sampled, the interview was designed to be no longer than five minutes. However, with some professionals it took 20 to 25 minutes depending on their willingness to share more information with the interviewer.

4.4.2.1.3. Limitations of the interview data

The written notes taken instead of audio recordings during the interview sessions could be highlighted as a limitation of the study. The majority of the interviews with parents, and almost half of the interviews with professionals, were tape recorded, but some respondents refused consent for recording but did consent to note taking. The accuracy of the note taking cannot be guaranteed as only one researcher was involved. Additionally, the questions

were not asked in sequence as it was not a highly structured interview, but a semi-structured one providing some flexibility and ease for the participant; therefore, according to the response of the interviewee, the sequence and the wording of the questions were modified. For respondents with high levels of literacy or understanding it was easy to administer the interview as it was presented, but for interviewees with lower levels of literacy or understanding, the interviewer had to explain the questions using simple wording or had to give examples to make clear the meaning of the enquiry.

One important issue to be noted was that the change in the sequence of questions or section of questions was not greatly dependent on the literacy or understanding level of participants, but to gain the interest of participants for those reluctant to open up or talk about their child's particular issues: the interviewer began with general questions about the services provided for children or about the services required in Pakistan, then moved on to more specific questions. Depending on the respondents' interest and response, the researcher sometimes asked questions related to the parent information pack first, while at other times began with information on the diagnostic facilities available in Pakistan.

4.4.3. Focus group with parents of children with ASD living in Pakistan

A focus group was also carried out with six (Bryman, 2008; Creswell, 2009; Rabiee, 2004) parents of children with ASD living in Pakistan. It was arranged to empower parents to contribute in discussion in a friendly atmosphere (Robson, 2002). Sharing of experience in a group setting is

likely to give confidence to shy parents who may fear discussing an issue in a formal interview setting. In addition, the focus group is ‘also useful in generating a rich understanding of participants’ experiences and beliefs’ (Gill et al. 2008, p.293; Stewart et al. 2008). Time and cost effectiveness also drove the study design (Robson, 2002).

Since six parents of children with ASD indicated their acceptance to participate in the study in the form of an nterview or focus group at the place and time of their choice (a hospital where they take their child for therapy), a focus group was considered appropriate and convenient. The reason for choosing a focus group over one-to-one interviews was access to the parents considering time and place. Parents of six children with ASD indicated that they could spare the time to participate in this study when their child attends a weekly class of two hours. As all six children happened to attend the same class the parents were expected to show up at the same time. Thus, a focus group was planned and discussed with the parents in order to address the issues above, and to gain the perspective of parents in a group setting to more fully represent the complexity of their world (Creswell, 2005).

The themes and questions of the focus group emerged from the questionnaires and interviews with a chance to explore them in more depth. They include issues related to support services available to parents of children with ASD in Pakistan and the needs of parents regarding an information and guidance pack, e.g. preferred format for receiving

information, suggested contents for the pack, etc. (see Appendix-G for focus group schedule).

Since note taking is difficult during a focus group as more than one participant speaks at any given time (Cresswell, 2005), it was tape recorded. The issue of recording was discussed with each participant before starting the focus group and all six participants consented to a recording. In addition, notes were taken during the focus group.

Design

The questions for the focus group were based on the same three themes used in the interviews (see ‘Design’ in 4.4.2.1.1).

Length

The length of the focus group was about one hour even though it comprised the same questions asked in the interview.

Recruitment Procedure

The parents who were contacted to complete a questionnaire were also asked about their willingness to participate in an interview or focus group (see 4.3). Six parents agreed to attend a focus group as it was convenient for them to participate when they took their child for a weekly session at a hospital in Karachi and usually have to wait outside the assessment room for a couple of hours while the child has their session. Thus, the focus group was arranged at the hospital for those who gave theirconsent to participate.

4.4.4. Analysis of interview and focus group data

Rabiee (2004) explained that the purpose of the study also drives the analysis. Krueger and Casey (2000) indicated that the analysis begins by going back to the intention of the study, and the success of the study requires a clear fix on the purpose of the study. Since very limited or no information, e.g. published papers, government records, etc., was available from any authentic source about the process of getting a diagnosis of ASD, the concerns of parents, the facilities or support services available for ASD children and their families in Pakistan, the quality of those services and many other similar issues, detailed, in-depth and comprehensive information on these issues was required to address the purpose of the study. Therefore, thematic analysis was considered appropriate for the present study as such methods of data analysis are 'most suitable where little or nothing is known about the study phenomenon' and 'uses the actual data itself to derive the structure of analysis' (Burnard et al. 2008, p.429). In addition, this is the most common approach used to analyse qualitative data (Burnard et al. 2008; Grbich, 2007; Guest et al. 2012; Pope et al. 2000; Rabiee, 2004).

Data was collected using focus group and semi-structured interviews with the participants and mainly consisted of open-ended questions. As a detailed understanding was required of existing practices about the services provided to ASD children and their families and many other similar issues, themes emerged both from the research questions and from the narratives of the research participants (Krueger and Casey, 2000; Rabiee, 2004).

The individual and focus group interviews were audio recorded, and subsequently the recordings were transcribed (Cohen et al. 2007). These transcripts were then provided to two researchers to verify the accuracy of them by comparing them to the recordings (Creswell, 2009). as the interviews were conducted in Urdu. As the interviews were conducted in Urdu the corrected version of the transcripts was then translated into English by two Urdu-speaking researchers who studied English at graduation level (MA in Teaching of English as a Foreign Language). Although, a few respondents used a mixed medium (answered one part of a question in Urdu and one in English), the majority preferred to answer solely in Urdu with one or two words of English used in places. The translated versions of the transcripts were compared with each other to find any differences and discussion was carried out with researchers until a uniform draft was agreed.

These transcripts were then subjected to a thematic analysis. The phases of the thematic analysis employed were conducted in line with the recommendations made by Burnard (2004), Burnard et al. (2008), Guest et al. (2012), Krueger and Casey (2000), Pope and Mays (2009), Pope et al. (2000), Rabiee (2004) and Ritchie and Spencer (1994). While investigating the analysis and assessing qualitative research in health care, these researchers had identified five stages of data analysis in the framework approach summarised as: (a) familiarization, (b) identifying a thematic framework, (c) indexing, (d) charting, and (e) mapping and interpretation (see

chapter 5 for further detail on how these data were analysed and themes emerged).

4.4.5. Survey of organisations working worldwide to support children with ASD and their families

A search was conducted of the relevant websites of different organisations working worldwide to support children with ASD and their families to discover their methods for providing support to parents of such children. A database of the different countries was created to identify the ways of providing support to the caregivers of children with disabilities as well as to discover if there were any support materials available on their websites which might provide some ideas for the format of the support pack to be developed (see database in Appendix-D, and 2.6 and 2.7 for a brief resume on the services provided by these organisations).

Different organisations working to support children with ASD and their families in developed countries such as Australia, Canada, France, Ireland, Japan, Spain, Netherlands, UK, and the USA, and in countries with similar economic or cultural background to Pakistan such as Bangladesh, China, India, Iran and the UAE were contacted and asked to supply sample material on parental support used and or developed by them, and also to give some suggestions on the format of a parent information and guidance pack. Material was received from the Irish Society for Autism, the National Autistic Society, PAPA NI and some other organisations from the UK, Canada and India. Furthermore, very useful suggestions were received via email from a

few organisations regarding the format and contents of a parent information and guidance pack (see chapter 6).

4.5. Ethics

The British Educational Research Association (BERA), (2011, p.5) stated that 'researchers should operate within an ethic of respect for any persons involved in the research they are undertaking', therefore, for the present study ethical issues were given special consideration, and endeavours were made throughout the research project to address the ethical issues as much as possible. To ensure that the tools likely to be used for the present study, and the process of administering them were undertaken with attention to all the ethical issues, the research tool developed and the process of administering it was presented to the Research Ethics Committee of the University of Wales, Newport. The tools were administered only after approval from the university's ethics committee (BERA, 2011).

The US Department of Health and Human Services (2004, p.19) and Denscombe (2003, p.134) further added that 'respecting the rights and dignity of those who are participating in the research project; avoiding any harm to the participants arising from their involvement in the research; operating with honesty and integrity' is the responsibility of the researcher. Ethical issues can be addressed by informed consent, and attention to matters of privacy and confidentiality (Wood and Kerr, 2011). Confidentiality is a very important matter which means protecting a participant's right to privacy (Gregory, 2003; Wood and Kerr, 2011). The essence of

confidentiality is that the identity of participant should not be revealed in the studywhich can be achieved by deleting their names and other identifiers (Cohen et al. 2007).

This issue was given important consideration during data collection as well as when reporting the results. Names of the participants are not mentioned throughout the dissertation. Rather than using their real names, coding was assigned to the participants in data analysis or discussion sections where there was a need to describe data in detail. The interview results especially were reported with care. However, the profession of the respondent was described in some places to indicate that this opinion came from the perspective of such and such professional. Conversely, in places while describing a few case studies reported by some professionals, the profession of the respondent was not disclosed either. One major reason for hiding the identity of the respondents was that there were very few allied specialist services for ASD children and their families in Pakistan. Diagnostic facilities were available in only two cities and other services were scarce to find anywhere in the country. Due to the limited understanding and awareness, not all the children who may have ASD receive a diagnosis. Thus, with the limited number of children diagnosed and the limited number of professionals working with these children and their families, reporting case studies including the professional's identity who narrated it might have resulted in the easy identification of the respondent. The respondent who reported the case studies also requested confidentiality. It is the responsibility of any researcher to respect the rights and dignity of those reporting as well as of

those about whom a case has been narrated. To avoid any harm to the professional who narrated the incident or the parents of the children whose case studies were presented, e.g. the results were published or were read by any third party, the results were presented in such a way that they did not lead to the identification of any of the respondent or the families presented in this study (Wood, 2005; Wood and Kerr, 2011).

A major tenet of research is that participation is voluntary (Creswell, 2008) because it respects the privacy and autonomy of the individual concerned; the research only stands to benefit if the participants feel safe that what they are divulging will not be used to identify them (Gregory, 2003). Another important ethical consideration as indicated by BERA (2011, p. 6) is 'the right of any participant to withdraw from the research for any or no reason, and at any time'. It was further added in the guidelines that the participant should be informed about their right to refuse to take part in the research or to withdraw from the study (BERA, 2011; Cohen et al. 2007).

Therefore, in the present study, parents of children with autism living in Pakistan, and professionals working with these families were contacted to seek their consent. Those who were willing to participate in the study were invited to complete the questionnaires. Those who completed the questionnaires were also invited to take part in a focus group or interview, with the freedom to refuse to take part in any of these or withdraw from the study at any time. Only those who consented to a focus group or interview were contacted later.

BERA (2011, p.5) indicated that ‘researchers must take the steps necessary to ensure that all participants in the research understand the process in which they are to be engaged, including why their participation is necessary, and how it will be used’. These steps are important for all research tools, but for interviews and focus groups their importance is doubled as it concerns interpersonal interaction and produces information about the human condition. Three main areas of ethical consideration were indicated by Cohen et al. (2007) as well as by the US Department of Health and Human Services (2004): informed consent, confidentiality, and the consequences of the interview or focus group. In respect of ethics, the researcher should explain to the respondent the purpose, scope and nature of the interview or focus group, and the use to be made of the data (Cohen et al. 2007). In other words, it should be made clear to the participant what the interview or focus group is all about, and they should be left in no doubt as to what will happen during and after the interview or focus group.

For the present study these issues were considered in the the cultural context of Pakistan. For the questionnaires, a consent form, a covering letter and an information sheet were attached detailing the purpose and nature of the study, the expected time to complete the questionnaire and information about the use of data. One cultural consideration was that people in Pakistan tend to avoid giving written consent for any kind of research study. Asking the respondents to provide written consent would have resulted in fairly limited participation, and would have aroused concerns or a perceived

threats among participants. Considering the cultural norm or practice of the country, the respondents were provided with a consent form but were not asked to return it with their name or signature included, therefore, most of the completed questionnaires were returned without any signed consent form.

The rationale for using a consent form in this study was to ensure that the standards of professionalism were aspired to. This is likely to become more common practice as more people become aware of research ethics and practices from developing countries during their professional degrees at reputable institutions in Pakistan or abroad. Therefore, a consent form was provided to the participants giving them a free choice of either oral or written consent. As the researcher had to visit the majority of the respondents personally (see sections 4.3 and 4.4), the most appropriate approach was used according to their level of understanding.

For interviews and focus groups the participants were informed about the purpose and nature of the study, use of data, and the expected duration of interview or focus group. The ethical considerations concerning recording an interview or focus group were met by getting the consent of the participants in advance. In some cases where participants did not consent to a recording, written notes were taken.

4.6. Issues of validity and reliability

Seale (1999, p.266) indicated as quoted by Golafshani (2003, p.601) that the 'trustworthiness of a research report lies at the heart of issues conventionally

discussed as validity and reliability'. These issues are very important in order to determine the worth of a research project. Wood and Kerr (2011, p.198) indicated that 'estimating the degree to which an instrument is valid and reliable is a critical step in the research process because this determines how much weight can be placed on the results', however it is to be admitted that data collection in the healthcare field 'is not a precise science'. Stenbacka's (2001) views also appear supportive to Wood and Kerr's thought that it is not precise to gather information about human perception, ideas, etc. (any sort of qualitative data). However, Stenbacka (2001) strongly opposed the emphasis on estimating validity and reliability of the instruments used to gather qualitative data, as she belies that these issues concern measurements which have no relevance to such data. Finding a middle ground in response to the views stated above, Golafshani (2003, p.602) said that 'to widen the spectrum of conceptualization of reliability ... Lincoln and Guba (1985) stated: "Since there can be no validity without reliability, a demonstration of the former (validity) is sufficient to establish the latter (reliability)".' Silverman (2006, p.132) on the other hand indicated that 'this is an important and complex issue with no easy answer'. Singh (1986, p. 102) however clarified that 'reliability and validity are two dimensions of the same thing, that is, test efficiency'. Wood and Kerr (2011, p.198) supported it by saying, 'whatever data collection method is used, the intent must be accuracy'.

Validity is defined as 'the extent to which the instrument measures' what it purports to measure, whereas, reliability refers to the 'consistency', 'stability',

and ‘repeatability’ of a data collection instrument (Gay, 1996, p.138; Linn and Gronlund, 2000; Miller, p.3; Wood and Kerr, 2011, p.209). To estimate the validity of the research instruments used in the present study, content validity (also named as evidence based on test content by Goodwin and Leech, 2003, p.183) was considered appropriate. Face validity is considered ‘a component of content validity’ (Miller, p.3) and only accounts for the apparent validation of an instrument (Wood and Kerr, 2011); it does not focus on checking that the instrument ‘actually’ measures what it ‘claims to measure’ (Singh, 1986, p.89). Content validity was preferred over concurrent and criterion reference validity because no standardised, pre-tested, valid instrument was available in the area of present study with which the tool designed for the present study might have been compared to or based upon (Gay, 1996). Predictive validity also did not fit the purpose as it focuses on accurately predicting some future occurrence, whereas the present study dealt with getting information about the support services provided to ASD children and their families in Pakistan, the views of parents about the services provided, the concerns of parents and many other similar issues (Wood and Kerr, 2011; Gay, 1996; Singh, 1986).

Wood and Kerr, (2011, p. 204) indicated that content validity ‘is estimated from the review of literature on the topic, or through consultation with the experts in the field, who have done unpublished research in the field’. Prior research literature was available on some areas of investigation, such as information or support provided to parents of children with ASD, and the time lag between first parental concern and diagnosis of ASD (Osborne and

Reed, 2008; Wiggins et al. 2006), but no previous studies were found on the provisions for ASD children and their families in Pakistan and similar issues. Therefore, the available literature review provided the basis of the research instruments used in the present study, but the validity was estimated through consultation with experts in the field (Gay, 1996; Goodwin and Leech, 2003). The instruments developed were judged or reviewed by professionals working with children with disabilities and/or working with ASD children and their families in the UK, USA, Pakistan, India and Dubai. Miller (p.3) indicated that content validity can be established by the review of 'ideally 3 to 5' reviewers familiar with the construct of interest. In the present study, more than 13 experts participated in the review process.

Experts' opinion was sought about the efficacy of the instruments developed for the present study from teachers, educational advisors, speech and language therapists, a doctor, a psychologist, and researchers in the relevant field. Two experts who reviewed the research instruments also had a child with ASD, while three others had either a child or a sibling with a disability. All the items of the instruments were reviewed for readability, clarity, relevancy and comprehensiveness (Goodwin and Leech, 2003), and the experts came 'to some level of agreement as to which items should be included in the final instrument' (Miller, p.3; Singh, 1986). The research instruments were reviewed and modified several times on the basis of the suggestions of the experts.

For the questionnaires, the interview schedule, and the focus group questions validity was established through consultation with experts (see section: 4.4.1, 4.4.2 and 4.4.3). Apart from the content of the instruments, a few important considerations which may affect the interviews and focus groups may include: bias on the part of researcher and respondent as these are related to human interaction (Cohen et al. 2007; Creswell, 2008), researchers' tendency to seek answers that support preconceived notions, misperceptions on the part of the interviewer of what the respondent is saying or misunderstandings on the part of the respondent of what is being asked. Wood and Kerr (2011) added that the relationship between researcher and respondent, and faulty recording or equipment failure can also lead to raise reliability issues. To achieve greater validity and reliability in interviews and focus groups, the amount of bias is to be minimized as much possible. Therefore, for the present study, following the consent of the participants, focus groups and interviews were audio recorded so that the interviewer may not have any misunderstanding of what the respondent was saying (Wood and Kerr, 2011). A few respondents did not consent to recording to take place, in such cases notes were taken during interview. The researcher also tried hard not to include any leading questions or ask questions that supported preconceived notions (Cohen et al. 2007).

To assist with the reliability of the questionnaire, Robson (2002) and Wood and Kerr (2011) recommended that questionnaires be piloted in order to check that they are worded in an unambiguous way. Item difficulty (Rani et al. 2004. p.308) and length of the questionnaire (Miller, p.2) is also linked

with reliability: if the items of a questionnaire are very difficult they may decrease its reliability (Rani et al. 2004, p.308). On the other hand, reliability value increases as the test length increases (Miller, p.2). Miller, however, pointed out that simply increasing the items may result in a low response rate, which is why the best approach is to develop a tool that completely measures the construct of interest and yet does so in an economical manner. These issues were given important consideration during the questionnaire development, and consultation with experts as well as a pilot study also helped in this regard. A pilot study has several functions, principally to increase the reliability, validity and practicability of the questionnaire (Cohen et al. 2007; Kumar, 2005; Oppenheim, 2000). Piloting involves a small scale test of the research methods so that any problems with the design are highlighted and can be altered before the main study takes place (Creswell, 2008). This also allows the researcher to consider the validity, reliability and practicality of the study in advance. Therefore, for the present study, the questionnaires were piloted to increase the efficacy of the instrument.

Another important issue regarding reliability of the interviews or focus groups is the format of the questions asked. Cohen et al. (2007) added that one way of controlling for reliability is to have a highly structured interview with the same format and sequence of words and questions for each respondent. On the other hand, Silverman (2006) argued for the importance of open-ended interviews, as these enable respondents to demonstrate their unique way of looking at the world – their definition of the situation. It recognises that what is a suitable sequence of questions for one respondent might be less suitable

for another, and open-ended questions enable important but unanticipated issues to be raised. Silverman (2006, p.118) further added that the difference in suggesting highly structured or semi/unstructured interview is due to how they are viewed. For the present study, semi-structured interviews were conducted. The same questions were asked to each respondent, but in any case where there was lack of understanding on the part of respondent, the questions were further elaborated.

An important consideration as indicated by BERA (2011, p.7) is that the 'participants may experience distress or discomfort in the research process', which may reduce his or her willingness to open up to an interviewer if the dynamics of the focus group or interview situation are too threatening (Kumar, 2005). Cohen et al. (2007) added that when 'reliability' is enhanced by rationalization, 'validity' would decrease. The main purpose of using interviews and focus groups in research is the belief that in an interpersonal encounter people are more likely to disclose aspects of themselves, their thoughts, their feelings and values, than they would in a less human situation. In other words, the distinctively human element in the focus group and interview is necessary to its 'validity'. Therefore, the focus groups and interviews were conducted in a friendly way that did not seem threatening to respondents or apply pressure to them (Wood and Kerr, 2011). Although, these were arranged according to the comfort of respondents regarding time and place (BERA, 2011), they were not forced to start interview instantly if other family issues required the parent's attention. In such cases the interviewer waited until the respondent completed such duties in order to

conduct the interview in a pressure free situation. Rapport was also developed with respondents so that they felt comfortable (BERA, 2011) and could ask about any misunderstanding of any question. The purpose and nature of the study was also made clear to them, and the use of data was also briefed to the respondents before arranging an interview or focus group.

4.7. Conclusion

This chapter described the methods and procedures carried out in the study. It presented a brief summary of how the study was developed and carried out as well as a brief description of the steps (phases) employed in the study combined with their justification. Data collection instruments used in the current study, the validity and reliability of those instruments, sampling procedure, and ethical considerations were also described.

The following chapter will present the analysis and interpretation of the data collected from parents of children with an ASD living in Pakistan and the professionals working with these families by using questionnaires, interviews and focus groups.

CHAPTER 5: ANALYSIS AND INTERPRETATION OF DATA

5.1. Introduction

In this chapter data collected from parents of children with ASD living in Pakistan and the professionals working with these families has been analysed and interpreted in detail. The first section of the chapter presents the results of a questionnaire, interviews and a focus group with the parents, while the second section describes the views of professionals collected using a questionnaire and interviews (see Appendices F to N for questionnaires, interviews and focus group schedule). The third section of the chapter presents a summary and discussion of the results.

This was a multiple stage study where each phase provided the basis for the next. The first three phases were related to the identification of the problem and the direction for the present study (see chapter 4). Phase four contained the main bulk of the study which had two steps: step one was related to the collection of data presented in this chapter, and step two comprised development of the parent information pack which will be presented in the following chapter.

5.1.1. Layout of the chapter[2]

For the purpose of clarity this chapter is divided into the following sections:

- 5.1.2. Analysis of questionnaire data
- 5.1.3. Analysis of interviews and focus group data.
- 5.2. Presentation of data collected from parents using a questionnaire, interviews and a focus group. It contains analysis and interpretation of data that identifies the current status of the diagnostic process of ASD in Pakistan, the support services available for ASD children and their families, as well as scoping the satisfaction of parents with the support services available. These data also provide the baseline information for the required pattern of parent information and guidance. For this section, the data will be presented as follows:
    - 5.2.1. Introduction
    - 5.2.2. Questionnaire results
    - 5.2.3. Interview results
    - 5.2.4. Focus group results
- 5.3. Presentation of data collected from professionals using a questionnaire and interviews. Data collected for this section relate to the concerns reported by parents of children with ASD living in Pakistan and professionals' consideration of the appropriate content and format for the parent information and guidance pack. For this section the data will be presented as follows:

[2] The term 'doctor' used in this chapter and at other places in the dissertation refers to the medical professionals as this is the term used in Pakistan for GPs, child specialists, neurologists, psychologists, psychiatrists, surgeons, gynaecologists, or any other medical professional with a specialisation.

- 5.3.1. Introduction
- 5.3.2. Questionnaire results
- 5.3.3. Interview results

- 5.4. Summary and conclusion, presenting the overall results drawn from the questionnaires, interviews and focus groups.

5.1.2. Analysis of questionnaire data

A statistical package for social sciences (SPSS) was used to analyse the questionnaire data. Different statistical measures, e.g. standard deviation, mean, weighted arithmetic mean, etc., were used to analyse and interpret the data depending on the nature of the question asked and purpose of the study behind that question (Alba and Bodfish, 2011; Fujiwara et al. 2011; Kumar, 2011; Neuman, 2005; Wiggins et al. 2006).

It is important to note that ‘n’ was used in this chapter to refer to the number of responses. Therefore, ‘n’ in a table means frequency of response.

It is also important to note that there were some missing data in the questionnaires completed by parents and professionals. As discussed earlier, a general trend in Pakistan is for people to avoid answering the questions which require written input from them. In the case of the present study, open-ended questions in the questionnaires were left blank by many respondents, meaning that the percentage did not total 100 in some tables.

5.1.3. Analysis of interviews and focus group data

Data collected using a focus group and semi-structured interviews with parents' and professionals' target groups were analysed using thematic analysis (see chapter 4). As a detailed understanding of the existing practices about the services provided to ASD children and their families and many other similar issues was required, themes emerged both from the research questions and from the narratives of research participants (Krueger and Casey, 2000; Rabiee, 2004).

Data were analysed in accordance with the suggestions made by Burnard (2004), Burnard et al. (2008) and Guest et al. (2012), Krueger and Casey (2000), Pope and Mays (2009), Pope et al. (2000), Rabiee (2004), and Ritchie and Spencer (1994). The five stages of analysis identified by them were summarised as (a) familiarization, (b) identifying a thematic framework, (c) indexing, (d) charting, and (e) mapping and interpretation.

Data can be analysed and managed using specialised computer packages, or by hand, but in either case open coding takes place (Burnard et al. 2008; Pope et al. 2000; Rabiee, 2004; Robson, 2007). In this case data were analysed by hand. As the first stage of familiarization with the data the audiotapes were listened to and the transcripts read and re-read by the researcher to get a sense of the interview as a whole. The next stage comprised identification of common themes and sub-themes arising in the responses to the questions. Words and short phrases summed up what was said in the text. Then all the words and phrases were collected and

examined for repetition and a list of topics was constructed. The next stage was to look for parallels within the topics. Grouping them together achieved a list with fewer themes, and a colour was assigned to each theme. The transcripts were then marked with the appropriate colour and the sections of text were cut and pasted under each of the theme headings using MS Word software (Pope et al. 2000).

A limitation of the analysis was that the coding framework was established by only one researcher, however, once the themes were drawn, two researchers were provided with the original transcripts and the emerged themes to give feedback. Any discrepancies in the coding were subsequently resolved in discussion with the researchers, and the coding was completed (Burnard et al. 2008; Creswell, 2009).

The data were then rearranged according to the appropriate part of the thematic framework to which they related. The coded data were then interpreted by considering their internal consistency, intensity, frequency and the extensiveness of the comments (Krueger and Casey, 2000; Rabiee, 2004). Simple counts were used to present data as they 'provide a useful summary of some aspects of the analysis' (Pope et al. 2000, p.114; Rabiee, 2004).

5.2. Presentation of data collected from parents of children with ASD

5.2.1. Introduction

This section comprises the views of the parent target group.

The following themes were focused on in the parent version of the questionnaire and interview as well as in the focus group:

1. The diagnostic process of ASD: the process of getting a diagnosis of ASD in Pakistan.
2. Provision of support services for ASD children and their families: identification of the support services available for ASD children and their families in Pakistan, and the satisfaction of parents with the services provided.
3. Required parent information and guidance pack: identification of the required pattern of parent information and guidance.

5.2.2. Questionnaire results

The tables and figures in this section present the results of the questionnaire data.

Table 5A: Demographic characteristics of the sample

Characteristics	n (%)
Respondents' relationship to the child	
Mother	36 (59)
Father	21 (34)
Grand parent	4 (7)
Gender of the child	
Male	43 (70)
Female	18 (30)
Respondents' address (city only)	
Lahore	11 (18)
Karachi	39 (64)
Multan	7 (11)
Missing data	4 (7)

The majority of the respondents were the mothers of the child with ASD (59%), 34% were the fathers, while 7% respondents were the grandparents.

The mean age of the children with ASD was 7.3 years (SD = 2.03; range: 3–11 years). The majority of these children were boys (70%). Most of the respondents were from Karachi (provincial capital).

Table 5B: Getting a diagnosis.

Characteristics	n (%)
Where diagnosed (city)	
Lahore	18 (29)
Karachi	39 (64)
England	1 (2)
Missing data	3 (5)
Child's age at first visit to a professional regarding child's difficulties	
0–1 year	27 (44)
1–2 years	25 (41)
2–3 years	6 (10)
Over 3 years	2 (3)
Missing data	1 (2)
Length of diagnostic process (from parental first concern or visit to any professional to diagnosis)	
0–3 months	1 (2)
3–6 months	2 (3)
6–9 months	1 (2)
9–12 months	5 (8)
Any other time span	48 (78)
Missing data	4 (7)
Number of visits to health or educational professionals before a diagnosis was given (approx.)(it was an open-ended question, the following categories were made on the base of responses)	
0–5 visits	2 (3)
So many visits/plenty/don't remember even/can't count (parent's views)	54 (89)
Missing data	5 (8)
Main reasons that led parents to take their child to a professional for diagnosis	
Parent read something about ASD	0 (0)
Parents found their child's behaviour different from other children	2 (3)
Somebody indicated that their child's behaviour was different from other children	16 (26)
Developmental delay – speech/other	57 (93)
Another child with ASD in the family	0 (0)
Any other	1 (2)
Missing data	1 (2)
Opportunity to revisit professional(s) who diagnosed the child in order to ask more question	

Yes	40 (66)
No	0 (0)
Parents(the respondents) who faced any problems with getting a diagnosis	52 (85)

Table 5B presents some background details to getting a diagnosis of ASD in Pakistan as reported by parents of children with ASD who participated in this study.

The child's mean age at diagnosis was 4.3 years (SD = 1.9); range: 6 months–10 years. The majority of the children were diagnosed in Karachi 64%, while the remaining 29% were diagnosed in Lahore. One child was diagnosed in England.

Nearly half the parents (44%) reported that their child was 0–1 year old when they first visited a professional regarding the child's difficulties. An average time lag between the first parental concern or visit to a professional and the diagnosis of the child was 36 months (range: 3 months–7.6 years).

About 89% of respondents reported that before a diagnosis for ASD was given to their child they had to visit health or educational professionals an excessive number of times and reported that they found it hard to count or remember the number.

The major reason that led parents to take their child to a professional for diagnosis was developmental delay (as reported by 93% of respondents). About 26% of respondents reported that in addition to the developmental

delay a further reason prompting them to seek a diagnosis was the identification by another person (which in most cases was the child's school teacher) of the difference of the child's behaviour from typically developing children.

About 66% of parents reported that they had the opportunity to revisit the professional who diagnosed their child in order to ask more questions. On the other hand, 85% of the respondents reported that they had faced many problems with getting a diagnosis of ASD for their child.

Facilities or support services provided for ASD children living in Pakistan

Approximately 89% of respondents in the parents' target group indicated that special schools for children with autism were available for their children in the city where they lived; whereas five respondents (8%) said that there was no special school for their child in their place of residence.

Unfortunately, there was no provision of staff within any mainstream school for children with ASD in Pakistan as reported by 97% parents who participated in the study. However, two people did not respond to the question.

In addition no respite care services were provided for ASD children in Pakistan as indicated by 90% respondents. The missing data for this question was 10%.

The provision of any other facility or support service for children with ASD was not indicated by parents either. In summary, parents reported that the provision for children with ASD in Pakistan were limited.

Information about the service provision

Further information was sought about the services provided for children with ASD. These included information about the location of the services provided, the provider of those services, and the quality of such services.

As previously indicated, there was no provision of staff within any mainstream school for children with ASD in Pakistan, nor was there any respite care service provided for such children. Moreover, no other facility or service for such children was indicated by parents who participated in the study. However, participants reported that a few special schools were made available for these children, therefore, further information about the location, service provider and quality of these schools was provided by the participants.

Over half the respondents (59%) reported that there was a provision of special schooling for children with ASD in Karachi; 23% added that this facility was also made available in Lahore. A few respondents (18%) did not answer this question possibly because the schools were available only in Lahore and Karachi, and those living in Multan would have left the column blank as there was no school for children with ASD in Multan. However, further information about this issue was sought in interviews and a focus

group details of which will be presented in the following sections of this chapter.

In answer to the question about service providers, 66% of the respondents reported that the services were not provided by the government but by private or non-governmental effort. However, 34% did not answer this question.

Satisfaction of parents with the special schools for children with ASD varied from person to person. About 11% of respondents reported that it was very poor, 13% indicated that it was quite poor, while 26% said that it was average. Only 20% of parents rated it as good.

Table 5C: Access to professionals for children with ASD and their families

S.No.	Q,11d. If you wish to see a professional regarding your child's difficulties, did you have access to that professional in your area?	Yes	No	Not needed	Missing data
		n (%)	n (%)	n (%)	n (%)
1	Speech and language therapist	49 (80)	3 (5)	3 (5)	6 (10)
2	Psychologist	55 (90)	1 (2)	4 (7)	1 (2)
3	Neurologist	54 (88)	1 (2)	5 (8)	1 (2)
4	Occupational therapist	50 (82)	4 (7)	2 (3)	1 (2)
5	Physiotherapist	54 (88)	4 (7)	1 (2)	2 (3)
6	Paediatrician	55 (90)	0 (0)	4 (7)	2 (3)
7	Any other profession:	0 (0)	0 (0)	0 (0)	0 (0)

A majority of the respondents (80%) reported that they had access to a speech and language therapist in their area if they wished to see them regarding their child's difficulties. Only 5% indicated that there was no

speech and language therapist in their area whom they could visit regarding their child's difficulties, 5% said that help was not needed, while 10% did not answer the question.

Additionally, 90% of the respondents reported that they had access to a psychologist in their area if they wished to see them regarding their child's difficulties, 88% had access to a neurologist, 82% had access to an occupational therapist, 88% had access to a physiotherapist, and 90% have access to a paediatrician. The access to or the availability of any other professional was not indicated by the respondents.

There was some missing data for this question as well which may be evident from the following tables (5D and 5E).

Table 5D: Information about the service provider and the location of the services provided for ASD children (access to professionals regarding child's difficulties)

S.No	Q.11e. If professionals were made accessible for your child, then in which city were these made available and by whom?	City				Who provided the support services?		
		Karachi	Lahore	Multan	Missing Data	Govt.	Private	Missing Data
		n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)
1	Speech and language therapist	33 (54)	15(25)	0 (0)	13(21)	0(0)	28(46)	33(54)
2	Psychologist	29 (47)	14(23)	3 (5)	15(25)	2 (3)	22(36)	37(61)
3	Neurologist	28 (46)	14(23)	3 (5)	16(26)	3 (5)	19(31)	39(64)
4	Occupational Therapist	32 (52)	14(23)	0 (0)	15(25)	0 (0)	24(39)	37(61)
5	Physiotherapist	32 (52)	14(23)	0 (0)	15(25)	0 (0)	22(36)	39(64)
6	Paediatrician	32 (52)	14(23)	4 (7)	11(18)	2 (3)	18(30)	41(67)
7	Any other profession:	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)

Further information was sought about the services provided for children with ASD including the location of the services provided and the provider of those services.

Only 5% of respondents from Multan indicated that they have access to a psychologist or neurologist, while 7% said that they had access to a paediatrician. Access to any other professional regarding their child's difficulties was not indicated by parents of children with ASD living in Multan.

About half the respondents (54%) reported that speech and language therapists were available in Karachi, while 25% added that these were in Lahore as well. On the other hand 21% did not respond to this question. Those who did not respond to the question perhaps did so because the speech and language therapists were available only in Lahore and Karachi, and those living in Multan would have left the column blank as there would be no therapist in their location, while some parents might have considered the provision inappropriate for their child. However, further information about this issue was sought in interview and focus groups, which is presented in the following sections of this chapter.

A few respondents (23%) reported that if they wished to see a professional regarding their child's difficulties, they had access to a psychologist, neurologist, occupational therapist, physiotherapist and paediatrician in Lahore. Nearly half the respondents (52%) indicated that they had access to an occupational therapist, physiotherapist and paediatrician in Karachi. 47%

said that they had access to a psychologist in Karachi, and 46% said that they had access to a neurologist in Karachi.

Nearly half the respondents reported that the services were not provided by the government, but rather by private or non-governmental effort. However, the majority did not answer to this question.

Those who did not answer the question about the location of the services provided might be those who did not have access to the professionals in their area, might not be satisfied with the services provided or might have some other reason for not answering this question. Missing data about the provider of services might reflect the respondents' ignorance of the provider of such services. Those who did not answer he question might be unaware, or might not be sure whether the professionals were hired by the government or were private practitioners. The interviews and focus group were used to explore this in more depth.

Table 5E: Information about quality of the services provided for children with ASD

Q. 11f. How would you rate services provided for your child?							
S.No	Professionals you might have seen regarding your child's difficulties	Rating scale (services provided by professionals)					Missing data
		Very poor	Poor	Average	Good	Excellent	Missing data
		n (%)	n (%)	n (%)	n (%)	n (%)	n (%)
1	Speech and language therapist	2 (3)	6 (10)	30(49)	7 (11)	0 (0)	16 (26)
2	Psychologist	0 (0)	0 (0)	28(46)	10(16)	0 (0)	23 (38)
3	Neurologist	0 (0)	0 (0)	31(51)	7 (11)	0 (0)	23 (38)
4	Occupational Therapist	1 (2)	3 (5)	33(54)	6 (10)	0 (0)	18 (29)
5	Physiotherapist	3 (5)	3 (5)	31(51)	4 (6)	0 (0)	20 (33)
6	Paediatrician	0 (0)	0 (0)	31(51)	5 (8)	0 (0)	25 (41)
7	Any other profession:	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)

Satisfaction of parents about the services provided varied slightly from professional to professional, however, none of the respondents rated the services provided by any professional as excellent. Nearly half the respondents reported that the services provided by all the professionals were average, however, 10% to 16% of respondents said that the services provided by the professionals were good. A few respondents reported that the services provided by a speech and language therapist, occupational therapist and physiotherapist were poor or very poor. There was some missing data for this question possible reasons for which had already been presented in the previous tables.

Table 5F: Information or training received by parents (if any) for supporting their child

S.No.	Q.13a. Have you received any of the following information or training for supporting your child?	Yes	No	Not Needed
		n (%)	n (%)	n (%)
1	Books, leaflets or booklets on ASD & its management	9 (15)	52 (82)	0 (0)
2	DVDs on ASD & its management	3 (5)	57 (93)	1 (2)
3	Website(s) on ASD & its management	13 (21)	48 (79)	0 (0)
4	Access to a discussion forum to talk with other parents about your child	14 (23)	16 (26)	1 (2)
5	Visit from a professional at your home to help you manage your child's behaviour	0 (0)	60 (98)	0 (0)
6	Did you receive a training programme from the following to understand and manage better your child's behaviour: a. TEACCH	1 (2)	59 (97)	0 (0)
	b. ABA	0 (0)	60 (98)	0 (0)
	c. SUN-RISE	0 (0)	60 (98)	0 (0)
	d. PECS	0 (0)	60 (98)	0 (0)
	e. Any other training:	1 (2)	57 (93)	0 (0)
6	Any other support (Please specify):	0 (0)	0 (0)	0 (0)

Only 15% of respondents indicated that books, leaflets or booklets on ASD and its management were available for them to read; whereas, 82% of respondents said that they had not received or read any book or leaflet on ASD and its management. Three parents (5% of respondents) reported that they had access to DVDs on ASD and its management, whereas, 93% reported that not a single DVD on ASD and its management was available for them. A few parents (23%) reported that they had access to a discussion forum to talk with other parents about their child. 21% indicated that they had gone through certain websites on ASD and its management for supporting

their child, while 79% reported that they had not searched, found, or gone through any website on ASD and its management.

Unfortunately, there was no provision of home visits from any professional to help parents manage their child's behaviour as reported by 98% parents who participated in the study. However, two people did not respond to the question.

In addition, no parent had received any training programme (e.g. TEACCH, Applied Behavioural Analysis, Picture Exchange Communication System, etc.) to further understand and manage their child's behaviour, except one mother who reported having received TEACCH and one mother who reported having received some other training which was not specified.

The provision of any other training was not indicated by parents . Above all, the results appear to indicate that there are very limited provisions for parents to gain information or training for supporting their child with ASD in Pakistan.

The quality of the information or training for parents about ASD

Further information was sought about the service provider and quality of the information or training received by parents for supporting their child with ASD.

Surprisingly, only two respondents responded to the question about a service provider, whereas a few responded to the question about the quality of the information or training provided.

One possible reason for the low response to this question might be the unavailability or lack of required support for parents of such children. Data presented in the previous table also indicated a similar situation. No participant had received or had access to any training (e.g. TEACCH, ABA, Sun-Rise, PECS, etc) to understand and manage their child's behaviour except for two mothers as reported by the participants. Likewise, there was no provision of home visits from any professional to help parents manage their child's behaviour. Only a few parents reported having access to books, DVDs, websites or discussion forums to gain understanding of ASD and its management.

Two respondents reported that the discussion forum where they could talk with other parents about their child was a private or non-governmental effort. No other respondent provided information about a service provider, even those who reported that they had access to a few books, DVDs or websites. This might be because only very few had access to any of these facilities, or they might not be satisfied with the services. Further information was sought in the interviews and focus group.

Satisfaction of parents with the information or training received was average. Two respondents reported that the books or leaflets read by them were

average, while three said that they were good. Three respondents indicated that the DVDs on ASD and its management seen by them were average. Rating of respondents about the websites on ASD and its management they had looked at was 'average' (as indicated by 8% respondents) and 'good' (as reported by three respondents). On the other hand, 7% reported that the discussion forum where they talked with other parents about their child was average, while two parents rated it as good.

Above all, the response to this part of the question was very low just like the previous part of the question, as very few parents had received any information or training for supporting their child with ASD.

Table 5G: Recommendations for the contents of the information and guidance pack for parents of children with ASD living in Pakistan

Q,14a. On the basis of your experience as a parent of a child with ASD, what would you like an information and guidance pack for parents of children with ASD living in Pakistan to contain?		
S.No.	Suggested parent information and guidance pack contents	**Mean response** Weighted mean (max 3) (Rating according to the need to be included in the pack)
1	Suggestions on behaviour modification	2.95
2	Suggestions for improving social interaction	2.93
3	Suggestions on promoting independent living (self-help) skills	2.82
4	Suggestions on handling sensory difficulties	2.80
5	Suggestions for improving communication	2.79
6	Brief introduction to ASD	2.11
7	Causes of ASD	2.05
8	Brief introduction of intervention approaches (e.g. TEACCH, ABA, Sun-Rise, PECS, etc.)	1.98
9	Any other	0

The parents of children with ASD living in Pakistan were asked to suggest the content for a parent information and guidance pack suitable to the Pakistani context. On the basis of their experience as a parent of a child with ASD they were asked to rate the contents according to the need for it to be included in the pack on a scale from 1 (not important/least important) to 3 (very important/most important). Each response was assigned a weighted value. For example, a rank of 1 (not important/least important) had an associated weighted value of 1, a rank of 2 had an associated weighted value of 2, while a rank of 3 was assigned a score of 3 points (Alba and Bodfish, 2011). The suggested contents for the pack with their respective weighted mean are listed in this table.

As indicated, parents of children with ASD were most concerned about the unusual behaviour of their child. A majority of the parents recommended that suggestions on behaviour modification should be included in the pack. Nearly all the respondents (96%) rated it as the most important information to be included.

Suggestions for improving social interaction was the second most important subject to be included in the pack as recommended by the respondents. Suggestions on promoting independent living skills (self-help skills), suggestions for handling sensory difficulties, and suggestions for improving communication were third, fourth and fifth (with a very slight difference of mean) to be included in the pack as recommended by the respondents. A brief introduction to ASD, the causes of ASD, and a brief introduction to

intervention approaches (e.g. TEACCH, ABA, Sun-Rise, PECS, etc.) were rated as relatively less important topics to be included. Parents recommended that these topics should also be included, but the topics discussed earlier were given priority by parents who participated in this study.

Table 5H: Recommendations for the format of the information and guidance pack for parents of children with ASD living in Pakistan

Suggested format of parent information and guidance pack	n (%)
Preferred language of the pack	
Urdu	60 (98)
English	1 (2)
Any other (please specify)	0 (0)
Preferred format of the pack	
Booklet	50 (82)
DVD	4 (6)
Website	0 (0)
Training/workshop	6 (10)
Any other (not specified)	1 (2)
Preferred duration of the training	
One day	1 (2)
Two days	1 (2)
Three days	1 (2)
Any other: morning only session	1 (2)
Any other: one hour	1 (2)
Any other (not specified)	2 (3)

Nearly all the respondents (98%) suggested that the language of the pack should be Urdu, while only one respondent said that the language of the pack should be English, making Urdu the preferred language of the majority for an information or guidance pack suitable for the Pakistani context.

With regard to format of the pack, 82% of respondents suggested that the parent information and guidance pack should be in the form of booklet; whereas 10% of respondents were in favour of a training workshop, preferring the information to be delivered directly as a training programme. On the other hand, 6% of respondents said that DVDs could be a good choice. In short, the majority of the respondents preferred the booklet format.

If their suggested format was a training or workshop, respondents were also asked how long they would prefer the duration to be. As only six respondents (10%) preferred training workshop over a booklet, it was thought that the question about the duration of the training or workshop would be answered by those six only, but interestingly the question was answered by seven respondents possibly due to a misunderstanding. There was a widely variable response for this question: of the seven who responded, one said that the training should be one day in length, one said that it should be for two days, one preferred a three-day training programme, one was in the favour of morning sessions, one said that it should be of an hour, while two respondents suggested that the duration should be more than three days.

5.2.3. Interview results

The findings of the interviews with the parents' target group are presented in this section. As discussed already, thematic analysis was employed to analyse the interview data (see section 5.1). The themes were developed both from the research questions and from the narrative of research participants. Simple counts were used to present the results of the analysis

5.2.3.1. Demographic characteristics of the sample

17 parents and one grandparent were interviewed for this stage of the study. The majority of the respondents were mothers of children with ASD (12), five were fathers and one was the grandparent of a child. The majority of the children with ASD were boys (78%). Most of the respondents were from Karachi.

5.2.3.2. Getting a diagnosis

When asking parents about their experiences of getting a diagnosis for their child, seven themes emerged from the narrative.

i. **Multiple consultations**

   All of the 18 parents who answered this question reported that they had consulted many professionals and visited many hospitals regarding their child's difficulties. The professionals consulted included paediatricians, psychiatrists and neurologists. They might then have seen other health professionals if recommended by the child specialist. They also reported that if they heard that there was a good hospital, clinic, government or private practitioner, they took their

child there, but in a majority of cases (15), the child's disability was not identified for several years despite having several consultations.

ii. Multiple diagnosis

15 of the parents reported that different professionals gave a different diagnosis or opinion about their child. In addition, nine parents explained that the diagnosis given by one professional did not match the diagnosis given by another.

iii. Incorrect diagnosis

15 of the parents reported that their child was misdiagnosed by the professionals. The diagnostic labels wrongly given by relevant professionals before the child was diagnosed with ASD were:

- by the neurologist, psychologist, paediatrician or other medical professional: mentally retarded (MR), slow learner, hyperactive, weak, underweight, having inappropriate brain growth.
- by the school principal or teachers: cerebral palsy (CP), slow learner.

In almost half of the cases (7) parents also considered diagnostic labels given by the child's teacher or school principal. For example, the mother of a 10-year old girl with ASD reported:

> *'... the owner of each school had a different opinion about her. Some said that she was a CP; some others were of the opinion that she was CP as well as ASD, while a few said that she was only ASD, and a few believed that she was a slow learner.'*

iv. Limited understanding of ASD among relevant professionals

In addition to the multiple or incorrect diagnoses given by relevant professionals as discussed above, five of the parents reported that doctors suggested medicine which did nothing to improve the child's symptoms. Rather, the child's behaviour got worse (kept on changing) as they grew. In two cases the medicine suggested for the child was vitamin syrup, medicine to control brain problem in two cases, and medicine for hyperactivity in one case. All these might reflect limited knowledge or understanding of ASD among relevant professionals.

v. Confusion of parents due to multiple viewpoints or lack of appropriate information

The majority of parents (15) said that no professional had told them what was 'wrong' with their child and why their behaviour differed from that of other children. The results indicated that parents had to deal with the confusion about their child's disability caused by the differing opinions of professionals which in a few cases did not match the child's symptoms. A mother of a girl with ASD reported: *'A big problem was that everyone had a different opinion about her, and everyone diagnosed her differently.'*

vi. Late diagnosis

15 of the parents reported that only after countless visits to professionals for several years regarding the child's difficulties, their child was diagnosed with ASD.The mother of an 11-year old boy with ASD reported: '*It took ten years to know that he is autistic. I knew it that he was special since he was a few months old, but did not know*

which sort of disability he had ... and doctors were unable to diagnose.'

vii. Pathway to diagnosis

All of the 18 respondents reported that the process of getting a diagnosis of ASD was not well organised in Pakistan. According to the majority of the respondents (13), it was a very long, complicated and disorganised process. The father of a 9-year old boy with autism reported: *'It was a very long, stodgy, painful and complicated process. Many doctors did not recognise the disability.'*

On the whole, the results of the interviews supported the results of questionnaire. All the respondents except one grandparent and one mother reported that they had faced many problems with getting a diagnosis of ASD for their child.

5.2.3.3. Provisions for children with ASD living in Pakistan

16 parents reported that special schools and therapy units were made available for children with ASD mainly in Lahore and Karachi. Three parents living in Multan indicated that there was no school for children with ASD in Multan, nor was there a therapy unit. The provision of any other facility or support service for children with ASD was not indicated by the respondents. According to the majority of respondents (14) the facilities or support services were usually provided by the private sector (i.e. non-governmental organisations).

The satisfaction of parents with the services provided was average in four cases or poor in twelve cases. None of the parents were happy with their child's school or therapist except one grandparent. All were quite unhappy with the quality of the services provided: they reported that the services were not effective and did not bring about any positive 'change' in the child or 'improve the child's symptoms'.

5.2.3.4. Information or training received by parents for supporting their child

14 of the parents reported that they did not receive any guidance from the professionals or any sort of training on handling children with ASD. Only two parents had read a few books on ASD and two checked on websites to understand the condition better. The mother of a boy with ASD reported: *'There was no one to guide us. It took too long to know what was wrong with the child and how to handle it.'*

5.2.3.5. Need for a parent information and guidance pack

When asked about the need for any information or guidance pack, all 18 parents reported that there was a need for such a pack. One parent reported:

> *'There must be some information pack for parents which should be given immediately after the child's diagnosis. We have been finding the useful stuff for a long time. There was no one to guide us. It took too long to know what is wrong with the child and how to handle it.'*

5.2.3.6. Recommendations for the format of the information and guidance pack for parents of children with ASD living in Pakistan

The suggestions of the parents' target group for the contents and format of the pack that was likely to be developed as a result of this study were as follows.

a) Suggested contents

The majority of the respondents (15) said that a brief and comprehensive booklet should be designed that would cover all the essential information about ASD. Just as in the questionnaire results, the parents were more concerned about the unusual behaviour of their child. 10 of the parents recommended that suggestions on behaviour modification should be included in the information pack. They also recommended that suggestions on improving social interaction and communication should be included. Three of the respondents further recommended that suggestions on promoting independent living skills (self-help skills), and a brief introduction on ASD with its causes should also be added.

c) Preferred language

All the respondents (18) suggested that the language of the pack should be Urdu.

d) Preferred format

According to the majority of the respondents (16), the preferred format for a pack suitable for a Pakistani context was a brief booklet. One respondent suggested a DVD and one recommended multiple methods including booklets, websites, DVDs, workshops and TV programmes. Conversely, the mother of a girl with ASD reported that

mothers could not spare the time for workshops or training as they had plenty of responsibilities including taking care of children and the family. She further added that sparing time to read a big book or more than one was also difficult for mothers, therefore, a brief booklet would be the most useful.

A grandparent of a boy with ASD added:

> *'There should be a booklet. It becomes handy you know. You can read it anytime, can carry anywhere. And in Karachi, there is a problem of electricity. You can't see DVD every time. The power fails most of the time.'*

In summary, the majority of respondents agreed that an Urdu booklet was the preferred format for the parent information and guidance pack.

5.2.4. Focus group results

This section provides the results of a focus group with parents of children with ASD living in Pakistan. As discussed already, thematic analysis was employed to analyse focus group data (see section 5.1). The themes were developed both from the research questions and from the narratives of the research participants. Simple counts were used to present the results of analysis (see section 5.1).

5.2.4.1. Demographic characteristics of the sample

Six parents of children with ASD living in Karachi participated in the focus group; five families were residents of Karachi, while one family was from Islamabad who moved to Karachi for the welfare of their son. The father of the child reported that there were no schools, therapy units or any organised services for children with ASD in their city at the time their child was diagnosed, therefore, they had no choice but to move to Karachi.

The group comprised six participants, out of which five respondents were mothers of children with ASD, and one was a father. The majority of the children with ASD were boys (5).

5.2.4.2. Getting a diagnosis

When asking parents about their experiences of getting a diagnosis for their child, seven themes emerged from the narrative.

i. **Multiple consultations**

   As in the interview results, all the parents reported that they had consulted many professional and visited many hospitals regarding

their child's difficulties. The professionals consulted included paediatricians, psychiatrists and neurologists. They might then have seen other health professionals if suggested that they do so by the child specialist.

ii. Multiple diagnosis

Five of the parents reported that different professionals gave different diagnosis or opinions about their child. They further explained that the diagnosis given by one professional did not match the diagnosis given by another.

iii. Incorrect diagnosis

Five of the parents reported that their child was misdiagnosed by the professionals. The diagnostic labels wrongly given by relevant professionals before the child was diagnosed with ASD were:

- by the neurologist, psychologist, paediatrician or other medical professional: mentally retarded (MR), slow learner, hyperactive, weak, having inappropriate brain growth.
- by the school principal or teachers: slow learner, mentally retarded.

iv. Limited understanding of ASD among relevant professionals

In addition to the multiple or incorrect diagnosis given by relevant professionals as discussed above, five of the parents reported that certain medicine was suggested for their child by the doctors which did nothing to improve the child's symptoms. Parents further reported that instead of taking the medicine the child's behaviour got worse with the passage of time. The medicine suggested for the child was

medicine to control brain problem in three cases, while two parents did not describe the type of medicine suggested for their child.

One mother further reported:

> *'Once I went to buy the medicine for my daughter which was prescribed by a neurologist. The drug seller at the pharmacy told me that the medicine I was willing to buy was for patients of severe mental illness. When I heard this, I stopped giving that medicine to my daughter.'*

One parent reported that each doctor had a different opinion about the child and suggested different medicine or tests. He added that at the suggestion of some of the doctors, his son went through a therapy with 'rays' in a hospital which did not improve his condition either. One mother shared that as her daughter had developmental delays and impaired communication she consulted many physicians. She further reported:

> *'Once I took her to a child specialist who told me that he'll release her tongue with some therapy and then she'll start talking. But when the specialist released her tongue, she became completely mute. Perhaps she got scared of the therapy or what, but she even stopped speaking the words that she used to speak earlier.'*

One parent added that the majority of the professionals were unable to diagnose ASD perhaps because they lacked knowledge of the condition or because they did not know how to diagnose it.

v. Confusion of parents due to multiple viewpoints or lack of appropriate information

All of the six parents said that no professional had told them what was 'wrong' with their child and why their behaviour differed from that of other children. Two parents further explained that they had to deal with the confusion about their child's disability caused by the differing opinions of professionals which in a few cases did not match the child's symptoms.

vi. Late diagnosis

All of the six parents reported that only after countless visits over several years to professionals regarding the child's difficulties was their child diagnosed with ASD.

vii. Pathway to diagnosis

All the respondents reported that the process of getting a diagnosis of ASD was very long, complicated and disorganised in Pakistan and that they had faced many problems before receiving a diagnosis.

5.2.4.3. Provisions for children with ASD living in Pakistan

Two respondents indicated that very limited facilities or support services were available for ASD children and their families living in Pakistan. All of the six respondents reported that there were some special schools and therapy units in Karachi which were usually a private or non-governmental effort. Satisfaction of parents with the services provided was average or poor. None of the respondents was happy with their child's school or therapist. They reported that the services were not effective.

5.2.4.4. Information or training received by parents for supporting their child

Five parents reported that they did not receive any guidance from the professionals or any sort of training on handling children with ASD. All of the six participants said that they only got a chance to meet other parents and share their problems with them. They further added that meeting with parents of children with ASD helped them understand the conditions associated with ASD to some extent.

5.2.4.5. Need for a parent information and guidance pack

When asked about the need for any information or guidance pack, all six parents reported that there was a need for such a pack. One parent further reported: '*Our problem is that we don't know how to deal with a child with autism ... the appropriate ways of dealing with ASD children should be told to parents.'*

5.2.4.6. Recommendations for the format of the pack

The suggestions of the parents' target group about the content and format of the information and guidance pack that was likely to be developed as a result of this study were as follows.

a) Suggested contents for parent information and guidance pack

All six respondents urged the need for a brief and comprehensive parent information booklet that would cover all the essential information about ASD. The results of the focus group supported the results of the questionnaire and interviews. Almost similar

recommendations were given by those who participated in the focus group. The recommended contents of the pack were suggestions for behaviour modification, improving social interaction, promoting independent living skills (self-help skills) and improving communication. The respondents also suggested that a brief introduction to ASD and its causes should be included.

b) Preferred language of the pack

All six respondents suggested that the language of the pack should be Urdu.

c) Preferred format of the pack

According to all six respondents the preferred format was a brief booklet. One respondent suggested a parent training workshop in addition to the booklet. When asked about the preferred duration of the training or workshop he further added that a two-hour session conducted once a week for three months would be a good choice.

In summary, all the respondents agreed that an Urdu booklet was the preferred format.

5.3. Presentation of data collected from professionals working with ASD children and their families

5.3.1. Introduction

This section presents the analysis of the views of professionals working with ASD children and their families in Pakistan. As discussed earlier, the section is divided into two sub-sections for the purpose of clarity: 5.3.2 Questionnaire results, and 5.3.3 Interview results.

5.3.2. Questionnaire results

The data that was collected from 54 professionals was tabulated by topic covering the following aspects:

1. Parents' concerns as reported to the professionals
2. Format of parent information and guidance pack: professionals' consideration of the appropriate content and format.

Table 5I: Demographic characteristics of the sample

Characteristics	n (%)
Respondents' profession	
Neurologist	3 (6)
Paediatrician	5 (9)
Psychologist	5 (9)
Physiotherapist	2 (4)
School principal	2 (4)
Educational advisor	5 (9)
Occupational therapist	2 (4)
Speech and language therapist	3 (6)
Teachers and teacher assistants	24 (44)
Missing data	3 (6)
Respondents' address (city only)	
Karachi	5 (9)
Multan	2 (4)
Missing data	47 (87)

The above table shows the majority of the respondents (44%) were teachers or teacher assistants. However, there was participation by all the professionals.

The number of professionals who participated in the study was low as awareness of autism was at an early stage in Pakistan, and there were only a few allied specialised services in Pakistan for children with ASD and their families. Moreover, the diagnosis facilities and other facilities such as special schools, speech and language therapy were available only in two or three big cities in Pakistan, thus all those involved in providing services to children with ASD were contacted by the researcher and invited to participate in the study. Many of them participated, some did not (see chapter 4 for details).

There were some missing data about the city of the respondents. As the researcher personally visited many of them and the questionnaire was completed then, or in some cases was left with the respondent and collected later, on the basis of a personal estimation the researcher can say that the majority of the respondents (almost 60%) were from Karachi, with some from Multan and some from Lahore. The respondents in many cases did not include their name or location, possibly due to their busy schedule, or the fact that as the researcher had personally visited them they assumed the information was already known. Considering such details unimportant might be another possible reason for leaving those columns blank.

Table 5J: Areas of concerns to parents of children with ASD

S.No.	Concerns about the child	Weighted average (max 5)
1	Behaviour problems	4.69
2	The child's education	4.20
3	Inappropriate or no use of language	4.13
4	Inappropriate or no social interaction	3.89
5	Sensory difficulties	3.85
6	Independent living skills	3.76
7	Stigma	3.76
8	The child's future – professional career	2.78
9	The child's future – adulthood	2.31
10	The child's future – marriage	1.33
11	Disclosure/who do they tell	0.72
12	Cure for autism	0.19

The professionals were asked to rank the concerns reported by parents on a scale from 1 (almost never reported/least frequently reported) to 5 (almost always reported/most frequently reported). Each response was assigned a weighted value. For example, a rank of 1 (almost never reported/least frequently reported) had an associated weighted value of 1, whereas, a rank of 2 had an associated weighted value of 2, a rank of 3 was assigned a score of 3 points, etc (Alba and Bodfish, 2011). The primary concerns with their respective weighted arithmetic mean are listed in Table 5J above.

As indicated, parents of children with ASD were more concerned about the unusual behaviour of their child. It was the most frequently reported concern with almost 85% of respondents to this question ranking it as parents most frequently reported or second most important concern.

The child's education was the second most common concern of parents, while difficulty with language (inappropriate or no use of language) was the third. Inappropriate social interaction, sensory difficulties, problems with independent living skills and stigma were the fourth, fifth and sixth common concerns with a very slight difference of mean. The concerns least reported by parents were disclosure, concerns about the child's adulthood, their professional career and their marriage. Respondents ranked these as concerns reported but not as a relatively important or of most frequent concern. It was also reported by the respondents that parents were sometimes concerned about the cure of autism.

Table 5K: Professionals' recommendations for the contents of the information and guidance pack

Q.3. On the basis of your experience as a professional working with children with ASD, what would you like an information and guidance pack to contain?		
S.No.	Suggested parent information and guidance pack contents	Weighted mean (max 5) (Rating in order of importance for inclusion in the pack)
1	Behaviour modification	4.63
2	Promoting independent living (self-help) skills	4.41
3	Improving communication	4.39
4	Improving social interaction	4.35
5	Handling sensory difficulties	4.26
6	Brief introduction to ASD	3.72
7	Causes of ASD	3.44
8	Brief introduction to intervention approaches (TEACCH)	2.74
9	Brief introduction to intervention approaches (PECS)	2.70
10	Brief introduction to intervention approaches (ABA)	2.54
11	Brief introduction to intervention approaches (AAC)	2.30
12	Any other content	0

On the basis of their experience as a professional working with ASD children and their families, the respondents were asked to rate the suggested contents in order of importance for inclusion in the pack on a scale from 1 (least important) to 5 (most important). Each response was assigned a weighted value. For example, a rank of 1 had an associated weighted value of 1, whereas a rank of 2 had an associated weighted value of 2, a rank of 3

was assigned a score of 3 points, etc. (Alba and Bodfish, 2011) (see Table 5K above).

As indicated in Table 5J parents of children with ASD were most concerned about the unusual behaviour of their child. Thus, the majority of the professionals recommended that suggestions on behaviour modification must be included in the pack. All the respondents rated it as either very important or the most important content to be included. None of the respondents considered it as moderate or the least important content.

Suggestions for promoting independent living skills, improving communication and improving social interaction were the second, third and fourth most important content (with a very slight difference of mean). Suggestions for handling sensory difficulties was the fifth most important content as recommended by the respondents.

A brief introduction to ASD, causes of ASD and a brief introduction to intervention approaches (e.g. TEACCH, ABA, Sun-Rise, PECS, etc.) were rated as relatively less important topics. The professionals recommended that these topics should be included, but theearlier topics discussed were given priority.

Table 5L: Recommendations for the format of the information pack

Suggested format	n (%)
Preferred language	
Urdu	53 (98)
English	0 (0)
Both	1 (2)
Any other	0 (0)
Preferred format	
Leaflet	0 (0)
Booklet	48 (89)
Fact sheet	0 (0)
Delivered directly as a training/workshop	4 (7)
Website	0 (0)
DVD	2 (4)
Any other	0 (0)
Preferred duration	
Half day	3 (6)
Evening session	5 (9)
One day	0 (0)
Two days	0 (0)
Three days	2 (4)
Any other (not specified)	4 (7)
Do you think it would be helpful to have the information divided into several packs?	
Yes	0 (0)
No	23 (43)

Nearly all of the respondents (98%) suggested that the language of the pack should be Urdu, while only 2% preferred both English and Urdu.

The professionals were also asked about their preferences regarding the format of the pack. A majority of the respondents (89%) suggested that information should be provided to the parents in the form of a booklet, 2% thought that a DVD would be a good choice, while 7% were in favour of a

training workshop. When asked about the duration of the training workshop, 14 professionals (26%) actually answered to this question, not just those who preferred a workshop over other delivery methods. One possible reason for this contradiction could be misunderstanding, or the respondent's willingness to suggest more than one format. Some respondents might have considered a training workshop as their second choice or that those who were not in favour of a workshop still gave their preference about the duration if it were to be preferred by a majority. 26% respondents answered this question, out of which 6% said that the training should be a half day, 9% preferred evening sessions, 4% were in the favour of a 3-day training programme, and 7% said that the duration should be more than 3 days.

The opinion of the professionals was sought about the division of the information into several packs and, if so, what each pack should contain. Nearly half of the respondents (43%) were in favour of a comprehensive pack rather than dividing the information into several packs. The remaining 57% did not give any opinion on the subject.

No respondent supported the idea of dividing the information into several packs. A majority was in favour of one comprehensive pack that may contain essential information about ASD.

Table 5M: Comments and suggestions

S. No	Q.9. Any other comments/ suggestion you would like to make?	n (%)
1	Do not add too many things/information in the pack	3 (6)
2	The pack should be interesting	2 (4)
3	It should motivate the parents	3 (6)
4	Practical information should be given	3 (6)
5	It should be brief	6 (11)
6	It should be to the point	1 (2)
7	It should be easy/understandable	4 (7)
8	It should be pictorial	2 (4)
9	Diet effect should also be presented in the pack	1 (2)
10	Information about a cure for ASD should be included	1 (2)
11	It should be of few pages only	4 (7)

About 6% of respondents suggested that extra or additional information should not be added to the pack; 11% presented similar views by saying that the pack should be brief, while 2% said that it should be to the point. In addition, 7% recommended that it should only be a few pages long. In other words, all these respondents suggested the pack should be brief and to the point. A few respondents suggested that it should be interesting, 6% added that it should be written in such a way that it motivated the parents, while 6% said that it should contain practical suggestions. About 7% of respondents added that the language of the pack should be easy to read and understandable. Two respondents (4%) suggested that pictures should be added, one said that effects of should be explained, and one respondent added that information about a cure for ASD should also be included. In short a majority of the respondents recommended a brief pack that was interesting and easy to read.

5.3.3. Interview results

This part of the analysis contains a brief description of the results of interviews with professionals by extracting the important themes from the interview data. Similar analysis was undertaken as with the parents, and simple counts were used to present the results (see section 5.1). The important themes that emerged from the data were:

a) **Parents' concerns:** the concerns reported by parents of children with ASD
b) **Need for a parent information and guidance pack**
c) **Format of parent information and guidance pack:** professionals' consideration of the appropriate content and format.

It was important to note that the professionals' interpretation of parents' needs and attitudes might have a set of personal biases (such as attributing marital difficulties within a family to the fact that their child has ASD when the parents have expressed conflicting views).

5.3.3.1. Demographic characteristics of the sample

16 professionals participated in interviews. The sample comprised three paediatricians, three psychiatrists, two occupational therapist, two speech therapist, two educational advisors, two teachers, a neurologist and a school principal. Most of the respondents were from Karachi.

5.3.3.2. Concerns, needs and common attitude of parents of children with ASD

When asking professionals about the concerns most often reported and the problems usually faced by parents of children with ASD, 15 themes emerged from the narrative:

i. Parental concerns about the symptoms of ASD

15 professionals who answered this question reported that the parents were most concerned about those areas that would be considered their child's core symptoms, such as repetitive, unusual or unwanted behaviour, inappropriate or no use of language and inappropriate social interaction.

ii. Concerns relating to academic achievement

Two professionals reported that parents were more concerned about the academic attainment of the child than their independent living skills.

iii. Concerns regarding a cure for ASD

11 of the professionals who participated in the interviews reported that a 'cure' for ASD was also among the most frequently reported concern of parents. They wanted to know about the chances of improvement in their child.

iv. Concerns relating to social stigma

11 respondents reported that social stigma was also a major concern.

v. Attitudes to acceptance of disability

While talking about the general attitude of parents, ten professionals who participated in the interviews reported that some parents were in the denial phase; they did not accept that their child had the disability.

One psychiatrist added that one possible reason for this attitude could be the social stigma: as people stigmatise any disease or disability related to the brain, parents may find it hard to accept that their child had a disease which was stigmatised by society.

vi. Confusion about treatment and schooling

11 of the professionals who participated in the interviews reported that a few parents were confused about the treatment or schooling for their child. Five respondents also indicated that most of the parents could not differentiate between what would be good for their child and what would be harmful. Three professional explained that parents sometimes kept the child at home which made their behaviour worse. One educational advisor reported:

> *Confusion of parents about treatment affects a child's wellbeing. As parents cannot differentiate what is good for the child and what is not, they keep on changing the child's schools and treatments. This takes away from the child the opportunity to settle down at one place and understand the environment.*

vii. Parental expectations

When talking about the concerns of parents, nine respondents reported that parents of children with ASD were looking for a 'magic stick' that might cure their child in no time. Parents' unrealistic expectations, limited patience and limited understanding were among the common attitudes as reported by the professionals. One teacher added that parents did not understand the complexity of autism. They expected that a few months' schooling would enable their child to

compete with typically developing children, thus putting pressure on the teachers and blaming them if the child did not perform academically according to their expectations. An educational advisor reported:

> *As the parents are unaware of the diverse symptoms and characteristics of ASD as well as appropriate ways of dealing with these children, they get depressed usually when they fail to handle their children with ASD, and start taking medicine for the relief of depression.*

viii. Parental motivation and feelings of optimism

It was also reported by eight professionals that parents lacked motivation and often lost hope about their ASD child; they thought that the child would not get better. A school principal added that parents often thought that their child was disabled and would remain like it forever. They thought that it was useless to do anything and they could not make any difference; thus they just stopped putting any effort into helping the child to learn or behave. Another important point indicated by the professionals was that many parents thought that the child would not change or improve, therefore, they did not want to spend much time on the special child. They preferred to spend time on their typically developing children from whom they could hope to get a return in the future. They thought that the disabled child might not be able to get a good job and support their parents financially.

Conversely, positive attitudes of parents to their child's disability were also reported by two respondents. One professional praised the optimistic approach of a doctor towards her daughter with Down's Syndrome (see case study 5 in Appendix E). This case study might reflect that all parents were not alike and some parents were not disappointed with their child. The professional who narrated this case study to the researcher added that the parents of this girl were admirable as they loved their daughter a lot.

ix. Parental desire for respite care

Eight professionals reported that parents wanted to keep their ASD children away from home as long possible. They wanted respite care or preferably a boarding school for the child, which might improve them and let the parents live a normal life. One school principal added that *parents did not want the ASD child at home. They ask us, 'if you can keep the child for a whole week, keep him'*. She added that parents not only want to keep their child away from home as long possible, but also want to get the services free of charge. They did not want to pay but would rather look for an institution that was run by a charity. Unfortunately, no boarding school or respite care services are available for children with ASD in Pakistan, but the professional just reflected on parents' attitude towards their child.

x. Blame and spousal support among parents

Another important issue highlighted by seven respondents was the attitude of child's father towards their wives. A teacher added that though many fathers were very loving and caring, and were greatly

attached to their special child, in a majority of cases they blamed their wives for the child's disability and showed non-cooperative behaviour. A school principal reported that according to her estimate, 99% of fathers of children with ASD blamed their wives for the child's disability and showed non-cooperative behaviour.

ASD's effect on family cohesion was also reported by one respondent (see case study 4 in Appendix E). The incident narrated by a professional concerned a lady's divorce because of her child with ASD. The professional reported that initially the couple had a very good relationship, and were greatly concerned about their child's treatment, but later on, the man divorced his wife. The professional reported that '*the underlying reason was the willingness to get rid of the autistic child.'* The case study reflected the potential pressure on a marital relationship. The professional indicated that the man left 'no stone unturned' to find any treatment for the child, but when nothing worked, he lost hope or became disappointed about the child.

xi. Roots to diagnosis and professionals' understanding of ASD

Another important issue highlighted by a psychiatrist, a school principal, an educational advisor, two teachers, and a paediatrician was that often children with ASD in Pakistan are undiagnosed. One psychiatrist discussed this issue in great detail. He reported:

> *The problem actually is that ASD is not diagnosed often in Pakistan. Professionals are not given any sort of training in diagnosis of ASD ... Behavioural sciences have started quite*

recently only in a few institutions of medical sciences. Only a few ... colleges who do offer it have added only general psychiatry as a part of the syllabus of doctors (which contains very basic information about child psychiatry, e.g. child psychiatry is this and this, it is the sub-speciality of so and so, etc.). Even in the King Edward Medical College, a child psychiatry department has only been established recently while there is no child psychiatry department in any other medical college ... The doctors who go abroad have some training on it. But the majority have only the basic training and thus are unable to diagnose ASD.

The point shared by the professional indicated that awareness of ASD is in its initial stage in Pakistan.

In addition five professionals reported that understanding of ASD is limited among relevant professionals. One paediatrician added to the point:

Here in Pakistan, some people sometimes open a school, find good names for it, such as 'save our soul' etc. But even those who open it do not know the difference between ASD, Down's Syndrome, mental retardation, etc. All children are treated in same way. Such practices should be eliminated.

This might indicate a limited understanding of the conditions associated with ASD even among the relevant professionals as well as their limited knowledge of the treatment approaches.

xii. Level of difficulties and school enrolment

One respondent reported that children with severe difficulties were not taken by special schools. The professional reported:

> *Special schools do not take ASD children with severe difficulties as they cannot handle these children. They simply refuse to enrol these children and offer admission to the children with mild difficulties. As a result, parents have to keep the child at home. They try to train the child, but they simply fail to do so. The child's behaviour gets worse with the passage of time as the parents have no training in handling a child with ASD. They do not know how to control the child's behaviour, what are the appropriate ways to deal with the child, etc.*

xiii. Sharing information

One interesting point indicated by an educational advisor was parents' tendency to hide useful suggestions or treatments from other parents. The respondent said that parents did not share knowledge with others in the same situation. They wished that their child should perform better than other ASD children and looked down upon other ASD children.

xiv. Social avoidance

One respondent reported that the parents did not take the child to social gatherings as the child made noises.

xv. Parents' understanding

Four professionals reported that parents' understanding was very limited. One paediatrician added that a few parents thought that 'an

evil spirit' had come into the child'. The ways in which mothers and fathers dealt with their child also varied from parent to parent. It was reported by two respondents and also observed by the researcher during interviews with parents that a few of them did not stop their children when they were acting inappropriately or misbehaving. They believed that suppressing the child might result in poorer brain growth; therefore they allowed the child do whatever they wanted. On the other hand, a few parents scolded their children quite badly even over small issues, and a few others beat them if they misbehaved.

In addition, one professional reported that a lady during her second pregnancy was forced by her husband to abort the child, as they already had a child with ASD (see case study 3 in Appendix E). The professional reported that the lady aborted the child unwillingly as *'her husband believed that if they had another child they might not be able to give proper attention to their autistic boy and his behaviour would get worse'.*

Four professionals reported that a few parents shouted at their children a lot, scolded them if they misbehaved, and a few others beat their children for their behavioural issues. One professional reported that a highly educated man in a very good post used to tie his 18-year old son with autism in iron chains, or beat him with a heated iron rod if the boy misbehaved (see case study 6 in Appendix E). The professional further reported that if the boy's mother ever tried to save

the child or requested any professional to counsel her husband, she was also beaten by her husband. The professional reported that: 'w*hen the ASD child was small he did not have many problems, his difficulties were quite mild. But his father is a very strict man. Perhaps due to his father's behaviour, the boy's behaviour has got much worse'.*

An educational advisor reported that '*parents are responsible for a child's behavioural problems'.* She said that the parents shouted at their child, scolded him, but did not try to understand what the child wanted. She and two other professionals suggested that *'there must be some content on this issue in the pack'.*

The concerns or issues discussed here also inspired the contents and format of parent information and guidance pack.

5.3.3.3. Need for a parent information and guidance pack

When questioned, all 16 professionals reported that there was a need for a parent information pack. One paediatrician said that it is very essential, that there must be such pack in Pakistan. He added:

In the whole world it has been arranged for people with all disabilities. Such ways have been devised which help these children grow well and control the severity of the disability. But unfortunately, little work is done here on disabilities, particularly on ASD. Thus there must be something for children with ASD and their families living in Pakistan.

5.3.3.4. Recommendations for the appropriate method of knowledge translation

The suggestions of the professionals' target group about the issues were as follows.

a) Suggested contents for parent information and guidance pack

As with the questionnaire results, priority was given to the topics: communication, social interaction, independent living skills and behaviour modification. The questionnaire data indicated similar results except for one topic which was 'suggestions on handling sensory difficulties'. In questionnaire data, this content was reported as an important content to be included in the pack, while in interview data it was recommended by six professionals, but not given high priority.

Additionally, the topic 'facts about ASD' was recommended by seven participants, 'a brief introduction of intervention approaches (e.g. TEACCH, ABA, PECS, etc.)' by nine participants, and 'information about the resources available for ASD children' by six participants. One occupational therapist and a paediatrician added that a few parents did not understand the condition and characteristics of ASD, thus the diverse symptoms of ASD should be described in the booklet with the paediatrician suggesting that it should be in the form of brief guidelines.

In addition some topics which were not identified by the professionals in the questionnaire were highlighted in the interviews. Eight respondents suggested that the pack should be written in such a way that it should motivate parents. A majority of the respondents (12) said that a brief information on a cure for ASD and the chances of improvement must be included in the pack. Two professionals added that parents sometimes got trapped by certain people who assured them that their child would be 100% cured by a certain diet or medicine only, thus not needing any other therapy or intervention. One educational advisor reported: *'a few parents do not accept that autism is a disability. They consider it a disease which could be cured by medicine'.* The respondent recommended that certain facts about autism must be provided in the pack. She further reported:

> *If the professionals living in Pakistan tell parents that ASD is a disability which cannot be fully cured, however there are chances of improvement in the child, the parents remain in doubt about it. But if they could see that it is written in a booklet produced in the UK, they would trust it. Thus there is a need to add a line on it.*

Other points to be included as recommended by one participant were: information about dietary intervention, the benefits of socialisation and that if any materials were referred to in the pack, they should be affordable and available.

b) Preferred language of the pack

Nearly all of the respondents (15) suggested that the language of the pack should be Urdu, but one occupational therapist considered that it should be designed in both English and Urdu.

One neurologist suggested that if it was permitted, the researcher should translate the NHS's booklets on ASD into Urdu. He reported:

> *Do one thing. Whatever health services are available there in the UK, the booklets provided by NHS on ASD, etc., translate those into Urdu. And then give the copies of that translated one to at least the Institute of Child Health and psychiatric units. It should be translated into Urdu, as you may be aware that very few people only in big cities can understand English and those can get information from the internet. But people living in the rest of the Punjab and other areas of Pakistan, can't use the information in English. Even in the UK, the booklets are translated into so many languages. They care for regional languages. You can also first make it in Urdu for accessibility purpose. Then if you want to expand your work, you can translate it into many regional languages after trying out the first one in Urdu.*

While an occupational therapist opposed the views of the neurologist by saying that *'here in Pakistan, we have to plan according to the values, status, and culture of Pakistan. Techniques used in the west*

cannot be copied as they are. Culture and values are to be kept in mind'. A school principal and an educational advisor also supported the views of the occupational therapist. They added that the problems of parents living here and their understanding level should be kept in mind while developing any material for them.

While talking about the language of the booklet one paediatrician added that the pack must be in Urdu. He reported: *'it must not at all be in English or any other language, as people can't understand it.'* He further reported:

> *People have a problem reading English. But there are no signs of Urdu books. Nobody has indicated anywhere that there is any literature available in Urdu here in Pakistan ... even people from very good families come to us, but due to the shame of being unable to read English, they did not tell us.*

In common with the suggestion of the paediatrician and neurologist, all the other professionals who participated in the interview recommended that the booklet should be written in Urdu. All were of the opinion that parents would not be able to read or understand it if it were written in English.

c) Preferred methods of knowledge translation

A majority of the respondents (13) suggested that the most appropriate method of providing information to parents of children with ASD in the context of Pakistan would be a booklet. Two professionals said that it could be in the form of a DVD, one recommended a

combination of approaches (e.g. booklet, DVD, counselling and workshops), while the remainder recommended a booklet. None of the professionals suggested a training session or workshop. They believed that training or workshops were not a good choice for the Pakistani context compared with a booklet or DVD due to time limitations, lack of money, a place to organise the training, availability of a resource person, suitable timing for parents, accessibility to a large population, etc. An educational advisor reported:

> *It would be difficult to arrange a training/workshop whenever a new child was diagnosed with ASD. The availability of a resource person in each city is not possible, and in Pakistan the system is not much organised. Even if some efforts would be made to organise a set up for trainings, it would finish after a certain period of time. If the booklet were developed instead of a workshop, it would be accessible to a larger group of people, and could easily be distributed in different cities of Pakistan.*

Another professional added that, *'a general trend in Pakistan is that housewives are expected to remain at home and in many cases it becomes difficult for the ladies to attend any training or workshops. Thus, arranging workshops might result in approaching a limited audience'.*

On the other hand seven professionals said that a DVD was not suitable to a Pakistani context either because of the problem of electricity in all areas of the country; power failures of up to 20 hours a

day in some areas could restrict the number of users able to see a DVD. Besides that, not all parents had computers at home due to their poverty and IT literacy was very low among the ladies in Pakistan. If there happened to be a computer and a generator (to generate electricity at the time of load shedding) in any house, there was no surety that the mother of the child would be able to operate the computer and see the DVD. An occupational therapist added that according to her experience *'only 2–3% of parents can be considered educated and can deal with their children quite well'.* A paediatrician reported that: *'a DVD is not a very good choice for Pakistani parents as the majority are not computer literate, thus it would limit access. Conversely, the booklet ensures greater accessibility and is quite handy.'* A principal further added: *'the mother of the child can read it any time, in any place, even when she is working in the kitchen'.*

Almost all the respondents (14) suggested that the parent information and guidance pack should be brief and to the point. Six suggested that it should be of a few pages only: they explained that parents living in Pakistan tended not to read any material if it were too long. The likelihood of a book being read would mainly depends on its length so it was very important to develop a pack as brief and to the point as possible. Nine respondents also suggested that it should be interesting, while five professionals said that it should contain practical suggestions. 11 respondents added that the language of the pack should be simple, indicating that the level of of parents' understanding

was quite low, thus the booklet should be easily readable and understandable. Three respondents added that very easy, brief tips should be given to parents.

In summary, a majority of the professionals recommended that the parent information pack should take the form of a brief, to the point and easily readable Urdu booklet.

5.4. Overall summary of the results

This part of the chapter comprises a summary of the results of data collected from the parents and the professionals in relation to the following research questions.

Research questions

Q.1. What is the current provision in Pakistan for children who may have ASD and for their parents?

Q.2. What are the current approaches to supporting parents of children with ASD in Pakistan?

Q.3. What is the most appropriate method of knowledge translation for parents of children with ASD in the context of Pakistan?

Lack of any completed research about provision for children with ASD in Pakistan did not allow any comparisons to be made between the findings of the present study and any completed research within a Pakistani context. However, results of the studies conducted on similar issues in other countries were combined in the discussion below to gain an understanding of

the issues, and to find similarities or differences. The results from the above research questions were divided into the following sections.

5.4.1. Facilities or support services provided for ASD children

The results of the study indicated that there were a lack of adequate services for children with ASD and their families in Pakistan. Not a single respite care unit was reported for the whole country. It was also reported that there were no provision of staff within any mainstream school in the country for such children. However, diagnostic facilities, a few special schools and therapy units for children with ASD were available mainly in Lahore and Karachi (the provincial capitals). Parents living in other cities, e.g. Multan, indicated that they did not have access to these facilities in their area, but had access to a few professionals in their area if they wished to consult them. Parents also reported that these professionals did not diagnose the child, but refered them to a provincial capital for a formal diagnosis.

Studies conducted in countries with similar economic and cultural backgrounds revealved similar situations in those areas as well. In Bangladesh, there were only 20 schools in the whole country for children with disabilities (Autismi- ja Aspergerliittory, Bangladesh, 2013). In many areas of India, no special schools for children with any disability were made available (Action for Autism, India, 2008; Sharan and Malhotra, 2007). Samadi and McConkey (2011) reported limited availability of services for such children and their families in Iran. In Malaysia the case was not much different; therapy centers were located in urban areas only, and the waiting

list was reported to be very long (The Malaysian Psychiatric Association, 2010).

5.4.2. Getting a diagnosis of ASD in Pakistan

The results of the study indicated that the child's mean age at diagnosis was just over 4 years (range: 6 months to 10 years). These results were similar with a few studies conducted in developed countries, e.g. the UK and the USA. Howlin and Moore (1997) and Howlin and Asgharian (1999) indicated a mean age of 5 to 6 years at diagnosis. Keenan et al (2009) found that the mean age at diagnosis was just over 4 years (range 1.7 to 13 years of age). Children's mean age at diagnosis was 4.5 years in Northern Ireland (NI) and 3.2 years in the Republic of Ireland (ROI). Wiggins et al. (2006) found that the mean age at diagnosis was just over 5 years in the USA.

In the same way, the results of this study were consistent with the studies conducted in other regions of the world concerning the time lag between first parental concern and diagnosis of the child. However, the delay noted in the current sample of Pakistani population was slightly higher when compared to other countries. The results of the present study indicated a mean time lag of 36 months (range: 3 months to 7.6 years) between the first parental concern or visit to a professional and the diagnosis of the child. In previous studies, Sivberg (2003) found a delay of 20 to 60 months between parental suspicion and diagnosis by a medical professional in Sweden. Keenan et al. (2009) found an average delay of 16 months in Northern Ireland (range 1–54 months) and an average of 14 months in the ROI (range 1–60 months).

Wiggins et al. (2006) found an average 13-month delay between initial evaluation and initial diagnosis in the US

Results of the study also indicated that parents had faced many problems in getting a diagnosis that mached their child's symptoms. Problems faced by parents included: countless visits to many hospitals, several consultations with professionals, incorrect diagnosis, late diagnosis (e.g. up to seven years in some cases) and different diagnostic lables where a diagnosis given by one professional did not match the diagnsosis given by another. Diagnostic labels wrongly given by relevant professionals before the child was diagnosed with ASD were: mentally retarded (MR), slow learner, hyperactive and cerebral palsy (CP). One reason for incorrect diagnosis may be the limited understanding of the condition among relevant professionals.

In a previous study, a delayed consultation with professionals was reported due to the parents' limited understanding of ASD and cultural beliefs. Indian parents delayed the consultation by considering that 'the child would be alright once grown up' (Kishore and Basu, 2011, p.162). This might reflect limited understanding of the condition among parents, but in the present study it was found that in some cases the professionals told the parents that their child would be alright once it had grown up. This might reflect a limited understanding of the condition among relevant professionals.

Limited understanding of ASD among relevant professionals had been reported for other developing countries as well (Action for Autism, India,

2008). Limited identification, assessment and diagnosis, even incorrect diagnosis, had been reported for many developing countries including Bangladesh, India and Iran (‘Autismi- jaAspergerliittory’, Bangladesh, 2013; Elsabbagh et al. 2012; Malhotra and Vikas, 2005; Samadi, 2011; Sharan, 2008).

In addition, this study showed that the process of getting a diagnosis of ASD in Pakistan was long, complicated and disorganised. Previous studies showed that the diagnosis process was long, distressing, unclear and difficult to understand for parents and families even in the UK (Cassidy and Morgan 2006; Keenan et al. 2009). But the situation in developing countries was even worse, where a lack of specialised diagnostic centres and appropriate screening or referral system had been reported (Action for Autism, India, 2008; Ethirajan, 2011; Malhotra and Vikas, 2005).

5.4.3. Information or training received (if any) by parents of ASD children for supporting their children

Data relating to the current situation of support services provided to parents of children with ASD in Pakistan revealed that parents did not receive any guidance from the professionals or any sort of training on handling children with ASD. In other developing countries the situation seemed slightly different in this respect. India offered a three-month training programme for parents called the mother-child program (AFA, 2013; Malhotra and Vikas, 2005). China also offered a training program, and in Iran a parent training programme ‘Omed’ was under trial in 2011 (Samadi and McConkey, 2011).

The results of this study seemed to be in harmony with studies conducted in other developing countries about the availablity of educational material in regional or national languages. The results of the present study indicated that a majority of the respondents did not receive or read any book, booklet, leaflet, or any other material on ASD and its management. A few parents had access to a discussion forum to talk with other parents about their child. A few parents also got a chance to meet other parents at their child's therapy centre or school, which enabled them to share their problems and to some extent helped them understand the conditions associated with ASD.

When compared with other countries, it was found that in India a booklet was made available for parents which was translated into regional languages as well (Malhotra and Vikas, 2005), but in Iran and Bangladesh there were no signs of any such material (Autismi- ja Aspergerliittory, 2013; Samadi, 2011). In Iran, parents updated their information about ASD from other parents in clinical waiting rooms (Samadi and McConkey, 2011). Lack of any systematic way of receiving information about ASD in India, Iran and other developing countries have also been reported (Malhotra and Vikas, 2005; Samadi, 2011).

5.4.4. Concerns, needs and common attitude of parents of children with ASD living in Pakistan

The results of the study indicated that the majority of the parents of children with ASD were most concerned about the unusual or unwanted pattern of

their child's behaviour, inappropriate or lack of language, inappropriate social interaction, and sensory difficulties of the child. Results of the present study support the research already conducted in this field. Alba and Bodfish (2011) found that a child's core symptoms of ASD, such as inappropriate social interaction, impaired communication and unusual or unwanted behaviours were the primary areas of concern for parents. Other studies also showed that a child's core symptoms and problem with independent living skills were among the major concerns of parents (Davis and Carter, 2008; Hall and Graff, 2011; Hastings and Johnson, 2001; Herring et al. 2006; Tomanik et al. 2004; Tomchek and Dunn, 2007). Social stigma had also been reported as an area of concern for parents in previous studies as well as in this one (Farrugia, 2009; Gray, 2002).

The findings of this study also showed that parents of children with ASD lacked patience, remained in the denial phase and sometimes lost hope about their child. Some of these attitudes had also been reported in previous studies. Studies have shown that parents' responses ranged from relief that the situation is finally clear, through shock, denial and uncertainty, to stress and sadness (Avdi et al. 2000; Marsell and Morris, 2004; Midence and O'Neill, 1999; Siegel, 1997; Wachtel and Carter, 2008).

The results of this study concerning parents' desire for respite care support the research already conducted in the field. Pisula (2011) indicated the importance of adequate respite services for parents and argued that caring for children with disabilities can prove challenging, demanding and tiring.

Respite care is needed to help parents satisfy their own and their family's needs (Cassidy et al. 2008; Farrugia, 2009; Fitzgerald et al. 2002; Montes and Halterman, 2008). In the present study, some professionals reported that parents wanted respite care and wanted to keep their ASD children away from home as long possible. One professional added that a few parents had indicated that they would like to send their child to boarding school in order to improve the child's symptoms and allow the parents to live a normal life.

Another common attitude of parents reported by some professionals was parents' confusion about their child's treatment and schooling. Parents' feelings of incompetence and anxiety as to whether they had made the right choice of intervention for their child has been reported previously (Renty and Roeyers, 2006; Pisula, 2011; Sharpley et al. 1997; Wachtel and Carter, 2008; Weiss, 2002). However, it was found in the present study that a few parents kept changing their child's school or did not send them to school at all. These attitudes might reflect a limited understanding of the condition among parents or dissatisfaction with the services provided. The results of the current study also indicated that parents' level of understanding was very limited. Similar results have been reported for Indian parents in previous studies. Kishore and Basu (2011) found that Indian parents delayed consulting primary health professionals regarding their child's difficulties due to limited understanding of the condition.

Another important issue discussed by professionals was the varying actions taken by parents. The professionals reported that some parents reportedly

shouted, scolded and beat the child if they misbehaved; while others did not stop them from misbehaving. Findings indicated that in one case the father of the child did not blame his wife for their daughter's disability and his love for his daughter was admirable (see case study 5 in Appendix E). Conversely, professionals reported far more servere responses by men to their wife and children with ASD including divorce, requesting abortion and severe beatings (see Appendix E). The potential reasons behind such varying actions taken by parents might include a limited understanding of the condition, being unaware of the appropriate ways to handle children with ASD or failing to communicate with the child properly. Other potential interpretations might include losing hope about the child's improvement, thinking that the child might not get better, or considering the child mentally retarded. Being unable to understand what the child wanted, and failing to teach the child appropriate ways of behaving in society might also contribute to parents' varying actions. Another potential interpretation could be the inappropriate support, guidance or advice given by the relevant professionals.

A potential effect of ASD on family cohesion and marital happiness had also been reported in previous studies. These studies indicated that providing appropriate information and guidance to parents is likely to prevent possible family breakdown (Autism Society, US, 2013; Brobst et al. 2009; Higgins et al. 2005). However, such varying actions taken by parents living in Pakistan might reflect their limited understanding of the condition.

5.4.5. Need for a parent information and guidance pack

Results of previous studies showed that providing appropriate information, guidance and training to parents of children with autism is an essential component of the child's welfare (Drew et al. 2002; Granpeesheh et al. 2009; Mahoney and Perales, 2003; Matson and Sipes, 2010; National Research Council, 2001). The results of this study also urged the need for an information and guidance pack for the parents.

5.4.6. Contents of a parent information and guidance pack

The results of the study indicated that a brief booklet that covered all the essential information about ASD would be appropriate for the parents. A majority of the respondents recommended that suggestions on behaviour modification, improving communication, social interaction, independent living skills, and handling sensory difficulties should be included in the pack. Respondents also suggested that a brief introduction on ASD, its causes, intervention approaches, information on a cure for ASD, symptoms of ASD, benefits of socialisation, and certain facts about autism should also be added.

Contents suggested in this study were the ones which were usually considered for parent materials by organisations working worldwide to support children with disabilities and their families (see chapter 6).

5.4.7. Appropriate methods of knowledge translation for parents of children with an ASD in the context of Pakistan (format of a parent information and guidance pack)

The results of this study support the research previously conducted in the field about the method of knowledge translation for parents. These previous studies found that using DVDs, websites, portals, forums and other information technology (IT) to transfer information to parents in developing countries might result in approaching a limited audience and might pose certain challenges due to poverty, limited IT literacy and power failure in resource poor settings (Heeks, 2005; NCDDR, 2005; O'Farrell et al. 1999; Westbrook and Boethel, 2005). The findings of the present study also indicated that the recommended method of knowledge translation for the parent target group, by almost all the respondents, was a booklet. A few respondents suggested that it could be in the form of a DVD or a training session, but the remainder who recommended a booklet were of the opinion that a DVD was not suitable to a Pakistani context. The reasons included the problem of electricity in all areas of the country, and low IT literacy among females in Pakistan. In addition, many parents did not have computers at home due to their poverty.

In addition, a majority of the respondents were of the opinion that training workshops compared with a booklet or a DVD was not a good choice for the Pakistani context due to several reasons including limited time, lack of money, a place to organise the training, availability of a resource person, suitable timing for parents, and accessibility to a large population. The

findings of this study were supported by previous studies conducted in many developing countries including Bangladesh, India, Iran and Pakistan. A shortage of mental health professionals and the lack of a trained workforce had been reported for these countries (Malhotra and Vikas, 2005; Sharan and Malhotra, 2007; Sharan, 2008; Syed et al. 2007; WHO, 2005). 'Dysfunctional health systems' (Elsabbagh et al. 2012, p.176; Malhotra and Vikas, 2005; Tareen et al. 2008), a limited health budget (US CIA, 2013), limited resources and mental health services (Action for Autism, India, 2008; Imran et al. 2009; Samadi, 2011; Sharan, 2008; Syed et al. 2007), geographic and economic barriers (Sharan and Malhotra, 2007) in developing countries including Pakistan also pose challenges to knowledge translation in such regions (Majdzadeh et al. 2008). In addition, Santesso et al. (2006) stated that a few studies conducted in developing countries indicated that providing health information to target groups using direct or interpersonal communication was not realistic due to limited resources, including human, financial and informational ones.

In common with the suggestion of parents, the professionals who participated in this study recommended that the booklet should be written in Urdu, as parents may not be able to read an English version. A study conducted in Iran on parents of children with ASD also highlighted the importance of developing parent information materials in regional or national languages. The study found that web-based information and international books were inaccessible sources of information for Irani parents due to their inability to read a text written in English (Samadi and McConkey, 2011).

5.4.8. Conclusion

This chapter presented the results of the data collected from parents of children with ASD living in Pakistan and professionals working with these families by using a questionnaire, interviews and a focus group. The results of the study indicated that current provision for ASD children and their families was very limited. There was no parent information and guidance pack currently available or used to support these children and their families and all the respondents expressed the need for such help. An appropriate method of transferring information to parents suitable to a Pakistani context would be a brief Urdu booklet. The reasons for this recommendation were discussed in detail by parents and professionals and were presented in this chapter. Respondents also provided suggestions about the contents of the booklet.

On the basis of the results and recommendations of this phase of the study, a booklet suitable to a Pakistani context was developed. Steps taken in this regard will be presented in chapter 6.

CHAPTER 6: MATERIAL DEVELOPMENT

6.1. Introduction

This chapter outlines the process of developing information and guidance material for parents of children with ASD living in Pakistan. In the light of the important considerations already discussed in chapters 3 and 4, an information and guidance pack was developed. The steps of material development identified by the KTA model were considered as guidelines.

The three stages of knowledge creation (CHIR, 2011; Graham et al. 2006) identified by Graham and others were:

- knowledge inquiry
- knowledge synthesis
- knowledge tools or products.

One important issue to be noted here is that these stages were embedded in the knowledge application or action cycle; the material development phase could not be separated from the other phases of the action cycle (see chapters 3 and 4). The material development phase is elaborated on in this chapter, while in reality the steps taken for material development occurred simultaneously with other stages of the overall process such as need assessment etc. Graham et al. (2006, p.18) also highlighted this issue: 'the action phases may occur sequentially or simultaneously, and the knowledge phases may influence the action phases'.

The chapter is divided into the following sections:

6.2. Knowledge inquiry

6.3. Knowledge synthesis

6.4. Knowledge tools and products

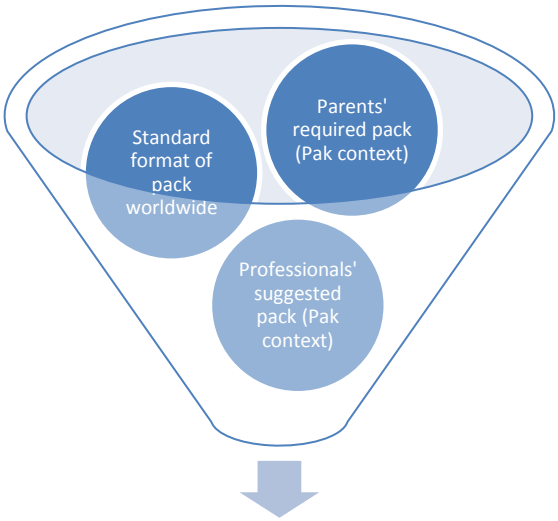
6.5. Conclusion.

6.2. Knowledge inquiry

The first stage of material development as identified by KTA theorists was knowledge inquiry which referred to the identification of the information that may be relevant to the required knowledge (CHIR, 2011). Graham et al. (2006, p.18) described 'the unmanageable multitude of primary studies or information of variable quality that is out there and that may or may not be easily accessed'.

For the study this stage consisted mainly of two types of knowledge inquiry, the collection of related knowledge followed by the identification of the required and suggested contents and format of the information pack. For clarity the second inquiry was divided into two, separating the required pack from the suggested pack (see Figure 6A).

Figure 6A: Intended outcome of the knowledge inquiry stage



Essential relevant information required for the development of parent information and guidance pack suitable for a Pakistani context

(Note: 'Pak context' in the figure above means 'Pakistani context')

The three intended knowledge inquiries as shown in Figure 6A were elaborated further in the following research questions:

Q.1. What format do information and guidance packs (for parents of children with ASD) take when used internationally?

Q.2. What sort of parent information and guidance pack would be appropriate to a Pakistani context?

Q.3. What are the needs of parents of children with ASD living in Pakistan regarding an information and guidance pack?

These questions were extension to the research question asked in the earlier chapters:

1. What methods are being used internationally for knowledge translation for parents of children with ASD?

2. What is the most appropriate method of knowledge translation for parents of children with ASD in the context of Pakistan?

As the study encompassed several phases for developing best practice principals, insight into certain topics was required at the stage of material development, therefore, more specific questions were gleaned from the general and comprehensive questions asked in earlier chapters. In addition, useful material development could not be segregated from the whole process. The steps were woven into each other to form a whole, so the research questions presented here were part of the series of questions asked for the entire study. Details of the questions and their link with the rest were documented in earlier chapters (see chapters 1 and 4).

To address these questions, material was identified or collected from different sources which were discussed under the following headings, merging the required and suggested pack under one heading.

- Identification of available knowledge
- Collection of required knowledge.

6.2.1. Identification of available knowledge

For this part of the process relevant material was identified or collected from different sources. This section of the chapter deals with that identification, and the detail of how the material was utilized for the present study is described in section 6.3: Knowledge synthesis.

Although identifying and reviewing material on ASD was the priority of the researcher, materials on other disabilities were not ignored, in order to identify any general patterns for providing information to parents of children with disabilities.

First, the relevant books, booklets, DVDs, information and guidance packs for parents of children with ASD or other developmental disabilities were reviewed using the library of the University of Wales Newport; The Dyscovery Centre, University of South Wales (an interdisciplinary centre of excellence for children and adults with specific learning difficulties); and the Autism Unit of Brynglas Primary School, Newport (where the researcher did her internship for MA SEN). In addition to that, notes provided in training courses attended by the researcher were also reviewed to identify the standard pattern of providing information to parents (see 6.2.1.4). In addition a search was conducted of relevant websites of the different organisations working worldwide to support children with ASD and their families to find out the pattern of support materials available. A countrywide database was created to find out if there were any support materials available on the website which might provide some ideas for the format of the information pack to be developed (see Appendix D for the database; and 6.3 for details on how the information was utilized for the present study).

A third approach was to contact organisations working to support children with ASD and their families in Australia, Bangladesh, Canada, China, France, India, Ireland, Japan, the Netherlands, Spain, the UK, USA and

UAE. The organisations were contacted and asked to supply sample material of parent support used and or developed by them, and also to give some suggestions on what such a pack might contain. This material was then reviewed thoroughly and the details presented below. References for all the materials reviewed are listed in the bibliography.

6.2.1.1. Books

Books produced by publishers specialising in ASD included David Fulton Publishers, NAS, Routledge, Sage, Speechmark, and Therapy Skills Builders. These were read thoroughly by the researcher and comprised manuals, information and training material for parents, activity sheets, suggestions on handling a child's difficulties, etc.

6.2.1.2. Booklets, leaflets and resource kits

Booklets and leaflets on diseases and disabilities were reviewed thoroughly, as well as resource kits for parents of children with disabilities or teachers working with these children.

Thematic analysis was undertaken to identify the common patterns for providing information to parents of children with disabilities(see Knowledge Synthesis below). Although the researcher's priority was identifying and reviewing material on ASD, material on other disabilities was also included where appropriate to consider formatting and content ideas.

The researcher reviewed booklets, leaflets or resource kits developed by the following associations: The National Autistic Society, UK; The Dyscovery Centre, University of South Wales, UK; NHS, UK; Autism Society of Newfoundland and Labrador, Canada; CanChild Centre for Childhood Disability Research at McMaster University, Ontario, Canada; Autism NI, Northern Ireland Autism Charity (previously known as PAPA); The Irish Society for Autism; East Sussex County Council, UK; Mental Health Foundation, UK; The Enuresis Resource and Information Centre (ERIC), UK; Autism Cymru, Cardiff, UK; Contact a Family in collaboration with Royal College of Paediatrics and Child Health, UK; Department for Children, Schools and Families, UK; Autism Education Trust, UK; NSW Ministry of Health, Australia; Department of Health, Centers for Disease Control and Prevention (CDC), USA.

6.2.1.3. DVDs, video cassettes and youtube videos on developmental disabilities

Sample material sent by Autism NI, Northern Ireland Autism Charity and The Irish Society for Autism included a DVD and a cassette. In addition, DVDs available at The Dyscovery Centre, UK, were included in the knowledge inquiry section and clips available on the internet were searched and viewed by the researcher to identify the pattern for providing information to parents in the form of electronic media. As this stage was related to collecting all the relevant information a variety of available information was searched and reviewed.

6.2.1.4. Materials or notes provided in parent training programmes, such as TEACCH or EARLYBIRD

The materials provided in the workshops or parent training programmes were also reviewed for the knowledge inquiry section. Attending trainings was an enriching knowledge inquiry experience for the researcher, as it enabled access to the materials used in such trainings. Training attended included the 'TEACCH parent training programme' organised by Division TEACCH, USA and sessions on the 'EarlyBird' parent training programme by the National Autistic Society (NAS), UK.

6.2.1.5. Guidelines on writing materials for parents of children with disabilities

When developing the material for parents (e.g. booklets, leaflets, websites, CD, etc), guidelines provided by agencies and organisations working worldwide to support children with disabilities and their families were consulted. The guides on writing material for parents or carers reviewed included: *A guideline developers' handbook* of the Scottish Intercollegiate Guideline Network (SIGN) for NHS Scotland, UK; *Developing effective print materials for low-literate readers* by the National Cancer Institute at the National Institutes of Health, US; and the US Department of Health and Human Services' *Toolkit for Making Written Material Clear and Effective* (a health literacy resource) comprising 11 booklets written for the Centers for Medicare and Medicaid Services (CMS). In addition, guides on writing easy material developed by the following associations were also reviewed: National Institute of Aging and National Library of Medicine, US; Health Canada, Ministry of Public Works and Government Services, Canada;

Northumberland Poverty Reduction Action Committee and Literacy Ontario Central South, Canada; Ontario Health Promotion E-Bulletin (paper by Wilby), Canada; Centers for Medicare and Medicaid Services (CMS), US; Plain Writing Act of 2010, US; Ontario Literacy Coalition, Canada; British Institute of Learning Disability (BILD), UK. In addition, the following books and papers were also reviewed: Berman, 2010; Birren, 1997; Bleicher, 2005; Crozier, 1999; Elliot and Maier, 2007; Fehrman and Fehrman, 2004; Goi, 2012; Hall and Hanna, 2004; Hemphill, 1996; Singh, 2006; Valdez and Mehrabian, 1994; Westland, et al., 2007; Wright, 1998; Wright, 2008. Guides for writers, editors, advertisers, etc. developed by Camden Print, UK and Colin Wheildon were also reviewed for their general suggestions on writing simple material for effective communication.

Guidelines on writing material for parents of children with disabilities were also provided by the organisations working to support children with ASD. The National Autistic Society, UK, sent a booklet containing guidelines on developing material for parents of children with ASD. The Autism Society of Newfoundland and Labrador, Canada; Families for Effective Autism Treatments of Alberta, Canada; and the Institute for Remedial Intervention Services (IRIS), India, also provided some useful suggestions.

Summary of the suggestions provided

A great deal of information on various issues of material development was provided in these guides including style of writing, layout, font size, style, use of headings, paper colour, text colour, reading ease, and many other similar

issues. A few examples are presented here followed by a summary of suggestions on developing easy reading material for parents of children with disabilities.

Brief, to the point and easy-to-read text are qualities of effective and user-friendly material for parents of children with disabilities (Health Canada, 1998; Ontario Health Promotion E-Bulletin, 2010; U.S. National Institute on Aging and National Library of Medicine, 2001). The Ontario Literacy Coalition, Canada (2000, p.11) indicated that 'many people believe that difficult language gives the writing more importance, or makes it better. Unfortunately, it only makes it harder to read'. The US Centers for Medicare and Medicaid Services (CMS), (2011, p.18) explained that 'writing complex sentences reflects our background and education. But we're not writing for ourselves – we're writing for our readers … Use the fewest words possible, but remember: your writing should be clear … not just brief'. The Ontario Literacy Coalition, Canada (2000, p.7) added that 'changing the way we write can make it easier for up to 26% more people to begin to get information from print'. SIGN, UK (2011, p.40) indicated that clarity of 'language and format' is of obvious importance, therefore, material for patients or their caregivers should 'be written in unambiguous language'.

Using pronouns is another tip for writing easy-to-read material for individuals with disabilities and their caregivers (Ontario Health Promotion E-Bulletin, 2010; US Department of Health and Human Services, 2010). The difference

that the use of pronouns can make is shown in the following example where pronouns are used in the 'plain writing version':

> **ORIGINAL VERSION**
> If applicant purports to represent an organization, a letter or other documentation that the applicant has authority to represent that organization is required to be submitted with this form.
>
> **PLAIN WRITING VERSION**
> You must include a letter or other document from your organization that says you are allowed to represent your organization.
> (US Centers for Medicare and Medicaid Services (CMS), 2011, p.16).

The guides reviewed made the following recommendations on developing material for parents:

- Material should be made as simple as possible, without sacrificing the content or compromising the meaning.
- Material should attract the reader's attention so the topic and purpose should be clear. It should look like it is worth reading and it is going to be easy to read.
- Material should hold the reader's attentionso it should be personally relevant, and be at the right level of detail for them. It should not be hard to read, distracting, confusing or of no interest.
- Material should be culturally appropriate, making readers feel that it was written for them. It should address readers' concerns or questions, and should use a friendly tone to make them receptive to the information.
- Material should be easy to understand and help move the reader to take action.

- Brief text that is to the point increases the possibility of material being read by the target audience. It should be brief, but at the same time should cover the essential information about a topic according to the needs of the target audience.
- The needs of the target audience should be kept in mind. Information should be organised in the way that the reader needs or expects.
- Short sentences increase ease of reading.
- Limiting each sentence to one subject also adds to ease of reading.
- Using short paragraphs and adding white space between paragraphs also helps the reader with understanding and finding the required information from the text.
- Including useful headings is another rule of plain writing. It saves the reader time and makes the writing more understandable.
- Black (or dark) colour text is easier to read.
- White (or light) coloured paper should be used for the background.
- Use of the active voice makes material easy to comprehend. At the same time, it also reduces the number of words used.
- Using common, everyday words helps to navigate a complex health issue in a helpful easy way.
- Direct communication also makes material user friendly. Pronouns pull readers into a document and make it relevant to them.

6.2.1.5.1. The use of specific font styles

In addition to general guidelines on developing easy-to-read material for patients or their caregivers in any language, a few suggestions regarding font

styles have been provided by the organisations or government agencies listed above.

As each language contains its own set of alphabets, suggestions on using fonts and the impact of font styles on readability of a text written in English is presented below, followed by suggestions for Urdu fonts.

6.2.1.5.1.1. The impact of using different font styles on readability in English text

Use of upper and lower case instead of all capitals was recommended in the guides reviewed. Debate on using capitals or lower case includes:

> There is, however, much to debate about the relative value of capitals and lower case … who favour capitals claim they have more impact on readers; those who prefer lower case claim their preference gives greater legibility. The latter argument is easy to accept, compare the facility of reading this paragraph with the following one:
>
> READING THIS PARAGRAPH IS A MUCH HARDER TASK. THE EYES HAVE TO GROPE FOR THE IDENTITY OF LETTERS, THENCE WORDS, TO COMPREHEND THE SENSE (Wheildon, 2005, p.61).

On the other hand, the limitations and benefits of using a font style with even strokes, or thick and thin strokes were also elaborated in the guides. There has been debate about the use of serif or sans serif fonts. Some argue that serif fonts help the reader to identify letters easily, which increases the reading fluency (Ali et al. 2013; Wheildon, 2005). Others claim that the thin strokes of serif fonts can make text harder to read for people with poor vision, while the clear, simple design of sans serif fonts increases the comfort and speed of reading (Ali et al. 2013; Ambrose and Harris, 2005; Bryan, 1996; Peck, 2003; Vaughan, 2008; Wheildon, 2005). The US National

Institute on Aging and National Library of Medicine (2001) recommended the use of sans serif fonts as it makes text easily readable. They suggested that the use of serif, novelty, and display typefaces should be avoided. Examples presented in their document (2001) include:

Sans Serif:
Helvetica
Arial
News Gothic

Serif:
Times New Roman

Novelty:
Old English Text

Display:
Bodoni Poster

Unlike the debate about the use of serif or sans serif fonts, there was no disagreement between the various organisations about the use of normal fonts instead of novelty, display, condensed, extra bold or heavy fonts. It was indicated in the guides reviewed that novelty styles and bold or heavy fonts decrease the ease and speed of reading and should be avoided.

6.2.1.5.1.2. The impact of using different font styles on readability in Urdu text

As the material for the current study was to be developed in Urdu as well as in English, an effort was made to identify literature on the best fonts to use in Urdu text. Unfortunately, only one paper was found on this topic. However

some literature on commonly used Urdu fonts and on the origin of Urdu scripts was identified.

Durrani and Hussain (2010, p.528) stated that ‘Urdu is an Indo-Aryan language, written using Arabic script from right to left’. The Urdu alphabet is a derivative of the Persian alphabet derived from Arabic script, which in itself is derived from the Aramaic script (Lewis et al. 2013; Wali and Hussain, 2006; Wikipedia Encyclopedia, 2013). Urdu is written in cursive and context-sensitive Arabic script in which successive letters join together (Hussain 2004; Hussain et al. 2004). Durrani and Hussain (2010, p.528) went on to say that ‘characters in general join with the neighbors within a word and in doing so acquire different shapes’. Wali and Hussain (2006, p.53) elaborated that ‘a letter can therefore have four forms depending on its location or position in a ligature. These are isolated, initial, medial and final forms … Shape of a letter depends on multiple neighboring characters’.

Arabic has many writing styles including Naskh, Sulus, Riqah and Deevani. Urdu is traditionally written in Nastaliq script, a commonly used calligraphic style for Persio-Arabic scripts (Wali and Hussain, 2006). Although, other writing styles such as Naskh are also used to write Urdu script, Nastaliq is the conventional and standard style for writing the Urdu language (Hussain et al. 2004; Sarfraz et al. 2011).

It is important to note that the names of Urdu fonts when written using English alphabets may appear different in different papers. Although in Urdu

the same characters are used to represent a particular font, different English spelling may be used by authors to better represent an Urdu term in written English. For example, the font ‘Nastaliq’ is spelled by Wali and Hussain (2006) as ‘Nastaliq’, by Hussain et al. (2004) as ‘Nastaleeq’ and by Sarfraz et al. (2011) as ‘Nastalique’.

As mentioned earlier, only one study by Sarfraz et al. (2011) was found on the readability of Urdu fonts. Their paper examined the suitability of Urdu fonts when used on websites. Sarfraz et al. (2011) reported that ‘Nafees Nastaliq’, ‘Noori Nastaliq’ and ‘Nafees Web Naskh’ fonts were found to be the most suitable fonts for use on the web for Urdu, and readability of ‘Nastaliq’ fonts were higher when compared to ‘Naskh’ fonts. Reasons of their high or low readability were not presented in the paper.

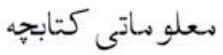
The factors which make an Urdu text easily readable were not discussed in the literature. To explore the issue further, guidelines for English fonts provided by the organisations listed earlier in this section were considered for accessible Urdu fonts. On reflection it appeared that certain suggestions provided for English fonts were suitable in the context of Urdu alphabets as well including the fact that normal fonts appeared easier to read when compared with condensed or heavy fonts. Examples include:

Normal fonts:

Noori Nastaleeq

معلوماتی کتابچہ

Naskh



Fonts of condensed strokes or heavy fonts:

Aseer

Aswad

Bombay black

Another issue to be considered for Urdu script is the use of fonts that display a character in its true form. To increase its readability the use of normal fonts instead of novelty ones is recommended even for English text. This becomes more crucial in the case of Urdu script in which letters join together to form a word. Any novelty style that changes the shape or does not represent the character in its true form may reduce the ease and speed of reading. For example:

Real shape of last (final) character of Urdu script followed by a word in which it is used:

Noori Nastaleeq font
Shape:

Word:

Novelty shape of the above alphabet followed by a word in which it is used:

Deevani font
Shape:

Word:

Jabeen font
Shape:

Word:

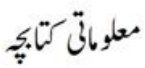
Sulus font
Shape:

Word:

Real shape of the second to last character of Urdu script followed by a word in which it is used:

Noori Nastaleeq font
Shape:

Word:



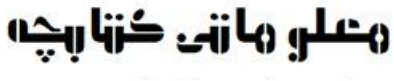
Novelty shape of the above alphabet followed by a word in which it is used:

Jaben font
Shape:

Word:

Mahal font
Shape:

Word:



Qamar font
Shape:

Word:

However, it is important to note that certain suggestions for English fonts may not be appropriate for Urdu text, such as guidelines regarding the use of upper and lower case, and the use of fonts with even strokes. Some examples of where the guidelines are not applicable to Urdu script include the existence of just one case for Urdu alphabets and use of thick and thin strokes for traditional Urdu calligraphy.

Suggestions on using Urdu fonts are summarised as follows:

- Using normal fonts instead of novelty, display, heavy or condensed fonts may increase ease of reading.
- Using fonts that display a character in its true form is another tip to be considered.
- Readability of ‘Nastaliq’ font is higher when compared to ‘Naskh’ font.
- ‘Nastaliq’ is the conventional, easy-to-read and standard style for writing the Urdu language.

6.2.2. Identification or collection of required knowledge

The second phase of knowledge inquiry for the present study included identification of a required pattern in parent information packs including the needs assessment and professional suggestions for a suitable pack (Kitson and Straus, 2011). Robson (2002, p.213) indicated that 'a select group of participants representing important constituencies, e.g. likely consumers of the services or users of the programme, providers and managers or administrators' were needed. Therefore, the present study involved parents of children with ASD living in Pakistan (for whom the package was to be developed), and professionals working with these families (neurologists, clinical psychologists, paediatricians, speech and language therapists, occupational therapists, teachers, educational advisors and a school principal). The following research tools were used for this part of the process:

- A questionnaire for parents
- Interview with parents
- A focus group with parents
- A questionnaire for professionals
- Semi-structured interviews with professionals

The rationale for this approach and the reasons for selecting these tools were presented in chapter 4, and the results obtained from these instruments were presented in chapter 5. How these results contributed to material development will be discussed below.

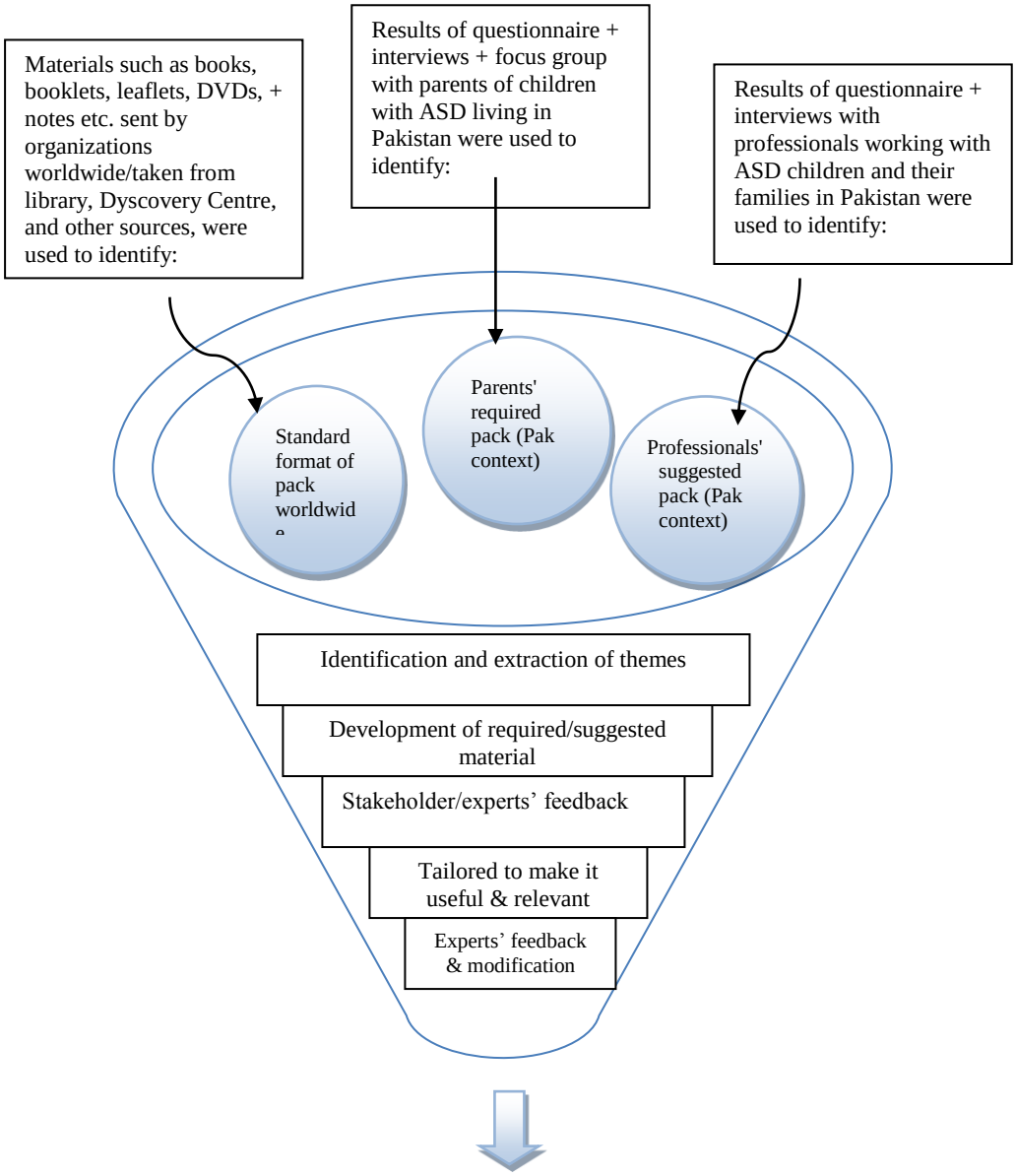
6.3. Knowledge synthesis

6.3.1. Introduction

This stage comprised developing material on the basis of the requirements of the target population and refers to ‘the aggregation of existing knowledge’. This may mean evaluating, blending and reproducing the information for the purpose of making it more useful for and relevant to the target audience (Graham et al., 2006).

The synthesis phase was represented in the form of a funnel to reflect the process of filtering the required themes, blending, modifying and reproducing information collected from a variety of sources to develop relevant, focused and useful material (see Figure 5B).

Figure 6B: Intended outcome of knowledge synthesis stage



Parent information and guidance pack suitable for a Pakistani context

6.3.2. Identifying themes, separating useful, relevant and required information from unnecessary data

As the present study is intended to develop information and a guidance pack for parents of children with autism living in Pakistan those examples written particularly for parents of children with disabilities were explored in great detail. The material written for individuals with disabilities, professionals, students, or anyone interested in the field were also reviewed to identify the

pattern for providing information about a disability (see Bibliography). The material was reviewed in relation to its format, content, key words, amount of information given, and style of providing information. Additionally, a general review covering identification of common patterns and thematic analysis of the material particularly written for parents was undertaken in detail.

The results of thematic analysis of 50 booklets and leaflets designed for parents of children with different disabilities are summarised below (see 6.2.1.2. for the names of the organisations concerned).

Target audience

The booklets and leaflets included in the thematic analysis were mainly aimed at parents of children with disabilities but 9 of the 50 appeared to provide information and guidance to any interested parties. These booklets did not exclude parents and carers; rather included others by using a more general style. For example, in a booklet named: *Dyspraxia/Developmental Co-ordination Disorder (DCD)* by The Dyscovery Centre, practical suggestions that may help a child with DCD were presented in the following way.

- Don’t overload the child with extra exercises when he may already be tired
- Ask the child what is bothering him and what he needs help with
- Make sure the child is always sitting comfortably but is posturally stable with feet on the ground and facing the task.

Conversely, in another booklet particularly written for parents by Professor Amanda Kirby from 'The Dyscovery Centre', UK, the suggestions were provided in the following way.

- If your child is doing homework create a calm and quiet environment
- Support your child and check they understand what they need to do
- Check if your child is sitting at the table that he or she is stable. Feet on the floor, and the table should not be too high for them, otherwise it may be hard for them to use a knife and fork.

Age range

A majority of the booklets provided information and guidance about young children with disabilities, however, 17 out of 50 covered all ages but with greater focus on childhood. It was noted that only four booklets out of 17 indicated that it was for parents of individuals with a disability, while the rest did not appear to mention that the booklet covered all ages. Those that appeared to cover all ages usually provided information and guidance on dealing with young children, with no suggestions, or very few, for adults with disabilities. It was noted that childhood was an important consideration in booklets for parents of children with disabilities.

The word used in 33 out of 50 booklets was child or children, whereas in 17 of the 50, the words used were: children, younger children, older children, adults, individual with autism, or people with autism, etc.

Length of the booklets

The mean length of the booklets was 25. The smallest were of six pages (named: *The good parenting guide* by Professor Amanda Kirby of The Dyscovery Centre, UK), and of seven pages (named: *Potty/toilet training* by Contact a Family, UK), whereas the longest was *Scottish Autism Information Resource: Next Steps* by The NAS, Scotland, UK. It was 119 pages long covering different areas of autism in detail in 12 sections like a combination of many booklets.

Conversely, the mean length of leaflets was 5.76 pages. The longest leaflet had 10 pages, while the shortest one only had two.

Reading age and reading ease

Random sampling was undertaken of booklets to ascertain reading age. One page was checked randomly from each booklet and showed the following:

The reading age varied between the booklets, and even between different paragraphs, from age 3–22 years. Mean reading age was 11 years, with a standard deviation of 3.44.

Just like the reading age, reading ease also varied between the booklets, and individual paragraphs of each booklet. Mean reading ease was 50, with a standard deviation of 17.91, ranging from 3.8 to 88.

Use of passive sentences also varied between the booklets, and paragraphs of each booklet from 0% to 66%. Mean usage of passive sentences in booklets for parents of children with disabilities was 15%, with a standard deviation of 21.

It was noted that the reading age and reading ease of different sections or paragraphs of a booklet varied a good deal. For example, the reading age of the suggestion section varied from the introduction section and other parts of the booklet. Some examples are presented below which show the results of randomly checked paragraphs from different pages of the booklets. It is important to note that the reading age of the booklets was checked using Microsoft Office which uses the term ‘grade level’ to refer to reading age.

Booklet A

Randomly selected paragraph 1:

Passive sentences: 66%, reading ease: 3.8, grade level: 22

Randomly selected paragraph 2:

Passive sentences: 0%, reading ease: 69.2, grade level: 11

Randomly selected paragraph 3:

Passive sentences: 0%, reading ease: 66.7, grade level: 5.6

Booklet B

Randomly selected paragraph 1:

Passive sentences: 50%, reading ease: 50, grade level: 10.6

Randomly selected paragraph 2:

Passive sentences: 0%, reading ease: 88, grade level: 3

Booklet C

Randomly selected paragraph 1:

Passive sentences: 0%, reading ease: 41, grade level: 11.8

Randomly selected paragraph 2:

Passive sentences: 33%, reading ease: 6, grade level: 19.8

In short, it was found that the language used in the booklets appeared to be very simple, easy and straightforward, but reading age did not appear to be a consideration and may need to be a recommendation especially if the readership is known to potentially have lower levels of literacy.

Style and format of the booklets

- In places when describing a child's difficulties, the words used were: the child may have, may appear, may find, autism impairs, it is associated, people have/display, seems not to, seek to, etc.
- When giving some suggestions to parents, communicative sentences were used instead of using informative sentences. The words used for providing tips to parents were: make sure, try to work on, ask the child, please remember, work with, slowly expose, structure your, etc.
- Brief and to the point information was provided to parents. Some topics were a sentence or two in length, while others could be a few paragraphs. It was noted that a topic was elaborated only to the extent that made it clear to the reader in a brief way. For example, in a booklet from The Dyscovery Centre only one sentence of two lines was used under the heading 'What is the incidence of DCD?', while

‘Key features of DCD in childhood’ were presented under 11 sub-headings on almost four pages of the same booklet. In other words, a topic was elaborated according to the needs of the audience as well as the requirement of the topic.

- Paragraphs, bullet points and headings were among the common styles used in almost all the booklets. Text boxes or question and answer style was used in almost three-quarters of the booklets. In two booklets some important sentences were centred, bold and coloured and the font size was doubled compared to the rest of the text. In almost half the booklets suggestions were given to parents in text boxes or with a heading, such as: Helpful tips, Ideas that may help, What practical suggestions may help the child?, Ideas to help, Ways to help. In two booklets, some important issues were presented in a Myth & Reality style, e.g. in a booklet from the Autism Society of Newfoundland & Labrador the style used was: Myth: Parents are too emotional; Reality: Because of their life experiences, those...’.
- At places in several booklets, pictures of children and/or objects were used, but it was noted that these did not particularly explain a situation or help with understanding. Only one or two pictures in a booklet for parents of children with disabilities appeared to assist understanding. On the other hand, it was found that the pictures used in the leaflets designed for patients of children with disabilities were communicative. It appeared that the pictures in those booklets elaborated on a condition or helped with understanding.

- The order of presenting information was similar in the majority of the booklets. Starting from the introduction of the disability; moving on to the causes, incidence, or facts about the disability; and ending with management suggestions for parents and references for further help.

Font style

Different font styles were used in the booklets but it was noted that in all booklets and leaflets the font styles that were used were easier to read. The font style used in different booklets and leaflets was as follows:

- Arial: 8 out of 50
- Times New Roman: 6 out of 50
- Comic Sans: 1 out of 50
- Tahoma: 1 out of 50
- Calibri: 1 out of 50

The rest of the booklets also used fonts similar to these which were easy to read.

In addition to identifying a general or standard pattern of providing information to parents of children with ASD, another important task was to identify the needs of the target audience. Graham et al. (2006, p.19) indicated that ‘generic knowledge is seldom taken directly off the shelf and applied without some sort of vetting or tailoring to the local context’. The needs of one group can be different from another, thus identifying the needs of the target group is essential in order to assure knowledge use. Tools used for this included a questionnaire, interview and focus group with parents of

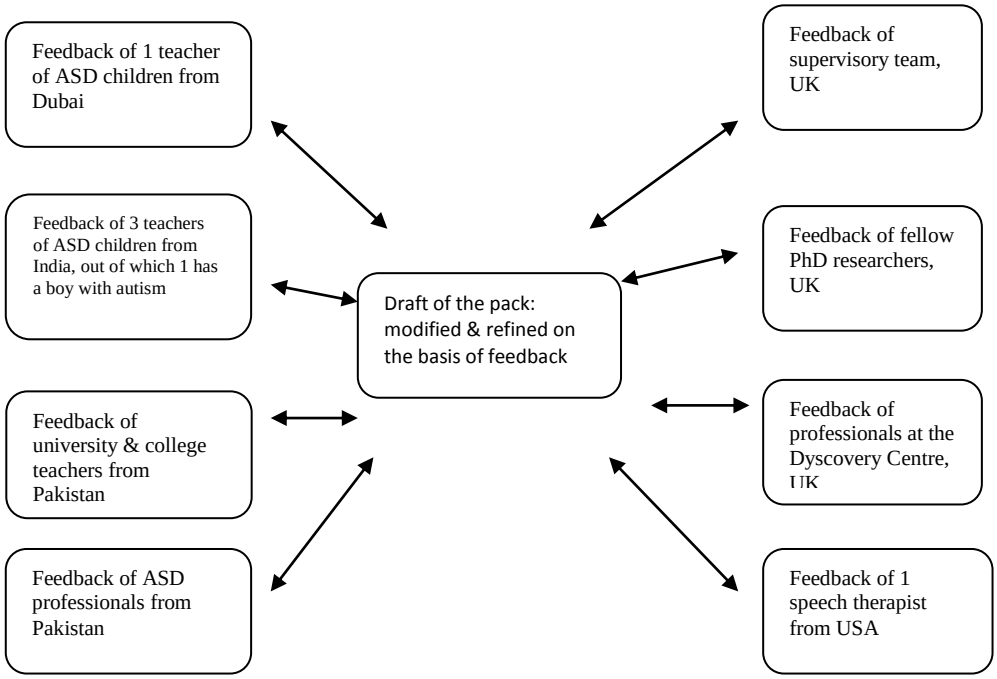
children with ASD living in Pakistan, as well as with professionals working with these families. The results of the research tools used in the present study identified the needs or requirements of the particular audience addressed, the problems faced by parents, and some issues to be addressed with the help of the information or guidance material.

6.3.3. Developing information and guidance suitable to a Pakistani context

On the basis of the data gathered, the parent information and guidance pack was developed by working with a range of stakeholders. The material was developed, piloted, then translated into Urdu, then piloted again. The issues considered during the process include the actual contents of the pack, its format and issues concerning design, length, content, use of medical terms and wider terminology, fitness for purpose, readability in English and then its translation into Urdu and associated challenges.

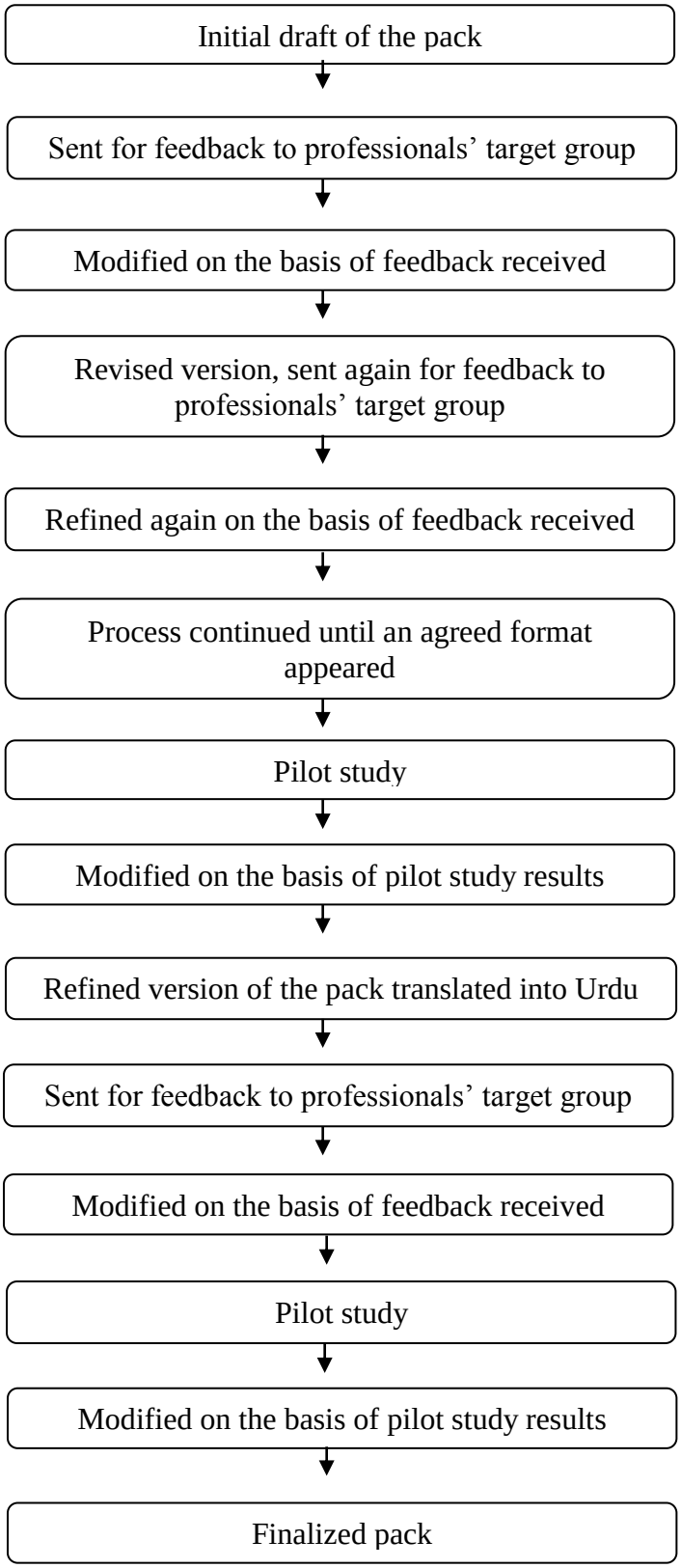
The guidance and feedback from many experts on the format and contents of the pack helped to make it focused and relevant to the needs of parents of children with ASD living in Pakistan (Graham et al. 2006; Robson, 2002). Discussions were carried out several times, between the researcher and supervisors; the researcher and fellow PhD students; and the team of health and educational professionals, including a psychologist with over 20 years experience, a medical practitioner with over 20 years experience at The Dyscovery Centre; and the professionals who worked or were working in India, Dubai, the USA and Pakistan with ASD children, in order to make the booklet more relevant to the needs of its target audience (see Figure 6C).

Figure 6C: Professionals involved in material development process



The information and guidance booklet for parents of children with ASD living in Pakistan was developed over several months. The process involved designing the initial draft of the pack on the basis of the information collected (see section 6.2.), distributing it among experts and professionals for their feedback, redrafting the contents once feedback was received, and then distributing it again among the experts for feedback and further refinement (Graham et al. 2006). The process of developing the pack is represented in the following Figure 6D.

Figure 6D: Process of material development



Once the English version of the booklet was developed, the following steps were taken to make it fit for purpose.

6.3.3.1. Piloting the English version of the booklet

The English version was piloted to test the actual content, format and length of the booklet, its appropriateness for the audience, and its readability. Those included in the piloting process were the researchers and professionals at The Dyscovery Centre, fellow PhD researchers, professionals working with ASD children in Pakistan, professionals working with ASD children in India and also in Dubai. On the basis of the results of the pilot study, the booklet was amended as suggested.

6.3.3.2. Translation of the booklet into Urdu

6.3.3.2.1. Introduction

A translation that stays true to the meaning of the original is quite challenging, therefore, to translate the English version of the booklet into a useful and effective Urdu version, the following considerations were taken in to account.

6.3.3.2.2. Some common problems with translation and suggestions to cope with these difficulties

The US Department of Health and Human Services (2010) provided the following guidelines on culturally appropriate translation:

- Literal translations can be a common error in translating a text. Word for word translation without making the meaning clear is often

confusing and misleading, therefore, importance should be given to the meaning and the message that make sense to the reader.

- A translator's lack of familiarity with the culture of the intended readership and their local language patterns and word use can result in an inappropriately translated text. Therefore, translators who are familiar with the culture and language pattern of the target audience should be given the task of translating the text.
- Effective translation from English into another language can be challenging because some terms and concepts are very difficult to translate in a meaningful way. As an example:

> Many … clients with limited English proficiency are immigrants or refugees from countries where health care is organized, delivered and paid for in ways that are very different from the American system in general … These clients have trouble understanding the concept of a health plan, no matter how carefully it is translated into their language … Here is an example … During an interview … a Vietnamese woman explained the meaning of 'health plan' ..: "'Health plan' is how and what I eat so that it is good for my health." (US Department of Health and Human Services, 2010, part 11, p.4)

- Some translations are done in a style that is not suitable for the purpose of the document and the intended readers; for example, the style might be too formal or too casual. Therefore, to avoid such problems, translators would need to be familiar with the typical social and language patterns of the intended readership.

- Translated text may contain errors but proofreading and piloting can help in identifying and removing those errors, therefore, translated material should be reviewed by multiple reviewers. These may include a sample from the target audience, independent proofreaders, and skilled people who are proficient in the target language and are familiar with the cultural context of the target audience.

6.3.3.2.3. Translation of the booklet into Urdu

Considering the pros and cons related to translation of a text, it was essential to assign the task of translating the booklet to a skilled person who would be familiar with the culture and language pattern of the target audience. Initially, the Ministry of Education in Pakistan, the deans and heads of Urdu departments of some universities in Pakistan, and those who were involved in literacy curriculum development, were contacted by the researcher to get their help in the translation of the parent information and guidance pack. Unfortunately, the researcher did not get a response from any of them.

After detailed discussion on the issue with the supervisors, utilizing other sources to make the Urdu translation of the booklet more reliable was considered. The steps taken in this regard included a literature review, translation of the booklet, and piloting the booklet in two phases. These are further described below:

a) Literature review: in addition to considering the guidelines for writing easy to understand material in any language for parents of children with disabilities by organisations worldwide (see section 6.2.1.5),

guidelines provided by these agencies (e.g. US Department of Health and Human Services, Ministry of Public Works and Government Services, Canada; and some others) on translating the material from English to another language were also considered. Moreover, a few booklets written in Urdu (published by Pakistani hospitals), or translated into Urdu (written in English but translated in Urdu for a Pakistani population living in developed countries, e.g. manuals, fact sheets, leaflets, booklets by Ministry of Heath, Australia; US Department of Health & Human Services; the National Autistic Society, UK; Contact a Family in collaboration with The Royal College of Paediatrics and Child Health, UK; Early Support, Department for Children Schools and Families (DCSF), UK) were also reviewed to identify a common pattern and style of writing for individuals with disabilities and their caregivers. (References for all the materials reviewed are listed in the bibliography.)

b) Translation: the booklet was then translated into Urdu by working with teachers of the Urdu language in colleges and universities in Pakistan. These people were involved in the translation process as they were not only familiar with the culture of the target audience, but had appropriate qualification in the target language (see section 6.3.3.3.2).

A strength of translating this booklet into Urdu was that it was not as challenging as translating some other materials could have been. Translating a material written for one population with certain cultural values, for another group of people with different cultural and language contexts has several

challenges and issues to be considered. In the case of the present study, although the material was initially written in English, it was written according to the needs, concerns, and wants of the target audience on the basis of the results of research tools used in the study. As it was intended for parents of children with ASD living in Pakistan even when initially written in English, the relevance of the material within the cultural context and needs of the target audience were not an issue at the time of translation.

6.3.3.2.4. Piloting the Urdu version of the booklet

Once translated the booklet was piloted in two phases to make it fit for purpose. Phase 1 comprised testing the Urdu version of the booklet in relation to its readability, appropriateness for the audience, general contents and accuracy of translation; while phase 2 comprised testing the Urdu version in relation to its usefulness. Parents of children with disabilities, professionals working with these families and teachers in the Urdu language in universities and colleges in Pakistan were involved in the piloting phase (US Department of Health and Human Services, 2010).

6.3.3.2.5. Modification and necessary revision of the Urdu version

On the basis of the results of the pilot study, which was conducted to test the readability of the booklet and its suitability to its audience, the Urdu version of the booklet was amended.

6.4. Knowledge tools and products

This stage of knowledge creation represents the intervention, ‘care pathways’, ‘practice guidelines’, or the final product that meets the needs of the target audience (Graham et al. 2006, p.18). The process of material development was discussed in great detail in the previous section 5.3: Knowledge Synthesis. It covered issues like identifying and segregating useful information, blending and reproducing information for the target audience, and evaluating the developed material to make it fit for the target audience.

This section of the chapter covers issues related to the appearance of the pack such as the front cover, the size of the booklet, font style, font size and the colours used. The issues considered for giving final shape to the parent information and guidance pack are presented below.

6.4.1. The cover page

Many designs and ideas for the front cover were discussed with supervisors and fellow researchers. Out of three designs, one was considered appropriate for the booklet. The design approved was of a tree given support by a man and a woman. The idea behind this was to reflect the importance of the care and support given by parents to a child with a disability. It was to symbolize that a plant grows into a healthy tree if proper care and a suitable environment is provided; likewise, the parents appropriate style of handling their children with ASD may help them to thrive. It was to convey to the

parents that they did not need to do anything unusual, but just needed to provide a suitable environment for their child to grow to their full potential.

6.4.2. Font style and size

As was noted in the results of the thematic analysis (see section 5.3.) the booklets and leaflets used fonts which were easy to read with the preferred font size being 12 point as used in 44 out of 50 booklets. Moreover, a review of guides on developing effective material (see section 5.2.1.5) also provided similar suggestions. Thus Arial was used for the booklet designed as a result of this study and the font size selected was 12 point. For the Urdu version of the booklet the font style used was Noori Nastaliq and the size was also 12 point.

These fonts were selected for the booklet as they were easy to read and were the preferred fonts in the majority of material written for parents of children with disabilities. One reason for selecting these font sizes for the booklet was the result of the thematic analysis that inspired the design of the booklet. The other reason for doing so were the suggestions and tips on developing easy-to-read material for patients and their caregivers provided by several organisations and ministries worldwide (see section 5.2.1.5). Moreover, the results of the need assessment process also supported the selection. Professionals working with ASD children and their families indicated that parents tend not to read a booklet if it is too long, therefore a booklet of a few pages would be suitable. The font size was selected to keep

the length of the booklet to fewer pages. A smaller font was not used as that might have caused problems to those with poor vision.

6.4.3. Colours used

Colours for the text and the background were chosen to be in harmony with the cover page with its brown and green shades for the tree design. Thus shades of green, brown and tan were used for the text in the booklet to reflect the links with nature and greenery. A lighter shade of olive green was used as a background with the text was in black and headings in dark tan.

The results of the thematic analysis (see section 6.3), and suggestions on developing easy-to-read materials for patients and their caregivers (see section 6.2.1.5) indicated that black text on white paper or dark font colour on lighter shaded paper was used in the material written for parents of children with disabilities. Additionally, a review of guides on material development indicated that coloured text may appear attractive and appealing to the reader, but may possibly decrease the readability of the material; while, a black printed page may appear boring, but results in a higher comprehension of the text.

Wheildon quoted Geoffrey Heard:

> The test outcomes which show that almost any departure from the standard of black serif type on white (or light) paper results in some interference to the reader's ability to read and comprehend text, are consistent with the results of psychological experimentation in these and related fields (Wheildon, 2005, p.141.).

Another reason for choosing these colours was its 'cooling' effect. Though red, yellow, and orange shades have a brighter appearance they tend to have a 'hotter' effect on the viewer. Colours such as green and brown which are in accord with nature are considered calming to the eyes, and can have a relaxing effect (Berman, 2010; Birren, 1997; Bleicher, 2005; Crozier, 1999; Elliot and Maier, 2007; Fehrman and Fehrman, 2004; Goi, 2012; Hall and Hanna, 2004; Hemphill, 1996; Singh, 2006; Valdez and Mehrabian, 1994; Westland et al. 2007; Wright, 1998; and Wright, 2008). In order to make parents feel relaxed and calm, these were the preferred shades.

6.4.4. Size of the booklet

Two options were considered: one was to make a booklet of A4 or legal size while the second was to make a booklet half of A4 or legal size so that two pages of the booklet would fit on an A4 sheet of paper.

The reason for considering these options was the accessibility of the booklet (US Department of Health and Human Service, 2010). As discussed already in chapter 1: Literature Review and Chapter 4: Data Analysis, limited resources were available in Pakistan for children with disabilities and their families. Moreover, there was no government support for this project. Thus it was thought that the researcher would distribute a few copies of the booklet to the relevant professionals throughout the country by using her own personal resources or with the help of some organisation and, as discussed with a few relevant professionals working in Pakistan, that the professionals

who received copies of the booklet might photocopy it to distribute to the parents who visited them regarding their child's difficulties. As photocopying is quite cheap in Pakistan it would increase the accessibility of the booklet if it were the size of paper normally used for photocopying.

The first option of making an A4 or legal size booklet was not selected because the results of data analysis (see chapter 5) indicated that parents tend to avoid reading books considering it a difficult and time consuming task. Thus, to avoid a bigger book-shaped pack and to make the booklet look different so that parents might not be hindered in reading it, a smaller size was preferred (US Department of Health and Human Service, 2010). Another reason for considering this size more suitable for the target audience was the psychological effect of it. As suggested by a few professionals (see chapter 5), a handy, small booklet which mothers could carry anywhere, even to the kitchen, would be more useful for the target audience and might increase the likelihood of the booklet being read. Thus, the size of the booklet considered appropriate for the target audience was half of A4 or A5.

6.5. Conclusion

This chapter has outlined the process of material development. It describes the step by step process of identifying or collecting useful and relevant information; filtering, blending, modifying and reproducing the information collected from variety of sources to develop a relevant, focused and useful information and guidance pack for parents of children with ASD living in Pakistan.

CHAPTER 7: EVALUATING PARENT INFORMATION AND GUIDANCE PACK

7.1. Introduction

This chapter presents the results of data collected to evaluate the information and guidance pack developed for parents of children with ASD living in Pakistan as a result of this study. The process of material development was presented in the previous chapter, while this chapter deals with the analysis and interpretation of data collected from the parents and professionals to evaluate the material (see Chapter 4: Research Methodology).

The layout of the chapter comprises:

7.2. Presentation of data collected from parents of children with ASD living in Pakistan

7.3. Presentation of data collected from professionals working with ASD children and their families in Pakistan

7.4. Conclusion.

7.2. Presentation of data collected from the parents

This section comprises parents' views on the effectiveness of the information and guidance booklet developed as a result of this study. The Statistical Package for Social Sciences (SPSS) was used to analyse the data collected using questionnaires with parents and professionals.

Demographic characteristics of the sample

Fifty one completed questionnaires were received, forty two of which were completed by parents of children with ASD and three were completed by grandparents of the child. However, in six completed questionnaires, the column of demographic information was left blank by the respondents.

The majority of the respondents were the mothers of a child with ASD (65%), however, in 18% of cases, the fathers of the child participated in the study. In addition, three respondents were the grandparent of the child.

Table 7A: An overall evaluation of the booklet by parents

Questions asked/characteristics	n (%)
As an initial booklet given soon after diagnosis, the amount of information covered:	
It covers a reasonable amount of information	49 (96)
It does not cover a reasonable amount of information	0 (0)
Missing data	2 (4)
Arrangement of information (format and organization):	
It makes sense	50 (98)
It does not make sense	0 (0)
Missing data	1 (2)
Usefulness of the booklet:	
Found it helpful	45 (88)
Did not find it helpful	3 (6)
Missing data	3 (6)
The way in which the booklet helped parents or their child:	
I found it very informative and useful	6 (12)
I got detailed information and understanding of my child's problems	3 (6)
I became aware of the underlying reasons for my child's problems or behavioural issues	3 (6)
Many queries which were in my mind were answered by it and things became clear	2 (4)
It enabled me to observe my child's habits/actions more closely	1 (2)
It enhanced my knowledge (about the disability)	1 (2)
The most useful topics covered in the booklet:	
All the topics	18 (35)
Questions and answers about a child's behaviour	5 (10)
Tips on communication (i.e. how to communicate with the child)	4 (8)
Characteristics of children with autism, and suggestions for their improvement	1 (2)
Facts about ASD, e.g. 'Mothers don't have any role to play in causing autism'	1 (2)
Least useful topics covered in the booklet:	
None/not a single topic was useless	13 (25)
However, final topics were very brief	1 (2)
Suggestions that may help the child were very short. These were very useful but adding more detail would increase its effectiveness	1 (2)
Leave it as it is, but develop more booklets of this kind which could provide details on each topic	1 (2)

Nearly all the respondents (96%) reported that as an initial booklet given soon after diagnosis it covered a reasonable amount of information. Two people, however, did not respond to this question.

Likewise, 98% of respondents reported that the arrangement of information (format and organization) made sense, while only one respondent did not answer this question.

One important thing note was that none of the respondents reported that the booklet did not cover a reasonable amount of information, or that the arrangement of information was inappropriate. This may reflect that participants were satisfied with the arrangement and quantity of the information covered.

When parents were asked how helpful they found the booklet, a majority of the respondents (88%) said that they found it helpful, while 6% reported that they did not find it helpful. Three people did not respond to this question.

The way in which the booklet helped parents of children with ASD was also indicated by quite a few respondent: 6% reported that they got detailed information or understanding of their child's problems, and 6% indicated that they became aware of the underlying reasons for their child's problems and behavioural issues. In addition, 4% reported that many queries which were in their minds were answered and things became clearer. One respondent

reported that it enabled them to observe the child's habits or actions more closely, while one said that it enhanced their knowledge (about the disability). 12% indicated that they found it very informative or useful, but did not mention any particular benefit they got from it.

The most useful topics covered in the booklet were also highlighted by the parents who participated in the study. About 35% reported that all the topics covered in the booklet were very useful. In addition, 10% reported that the question and answers about children's behaviour were among the most useful topics covered in the booklet, while, according to 8%, suggestions on how to communicate with the child were reported as very useful. One participant said that the characteristics of children with autism and suggestions for improvement were the most useful topics covered in the booklet, and one respondent reported that the 'facts about autism (e.g. mothers do not have any role to play in causing autism)' was the most useful topic covered in the booklet.

When participants were asked to report the topics they found least, 25% said that not a single topic was useless. One participant added that the last topics were, however, very brief, and one reported that the suggestions that may help the child were very short. The respondent further reported: *'Though these were very useful, but adding more detail would increase its effectiveness.'* Conversely, one respondent suggested that further details should not be added, but that developing more booklets of this kind to provide detail on each topic would be quite useful.

Table 7B: Evaluating the booklet regarding its contents and format

Please rate the booklet on:	n (%)
Language	
Easy to understand	44 (86)
Acceptable	5 (10)
Hard to understand	1 (2)
Size	
Far too small	0 (0)
Acceptable	50 (98)
Far too big	0 (0)
Font size	
Far too small	1 (2)
Acceptable	49 (96)
Far too big	0 (0)
Length	
Far too short	2 (4)
Acceptable	48 (94)
Far too long	0 (0)
Colour scheme	
Far too dull	3 (6)
Acceptable	47 (92)
Far too bright	0 (0)
Content relevance	
Very relevant	46 (90)
Relevant	4 (8)
Irrelevant	0 (0)
Content usefulness	
Very useful	49 (96)
Useful	1 (2)
Useless	0 (0)
Detail of topics	
Very good detail	45 (88)
Good detail	4 (8)
Poor detail	1 (2)

The satisfaction of the parents with the language of the booklet varied slightly from person to person. A majority of the respondents (86%) reported that the

language used in the booklet was easy to understand, 10% indicated that it was average, while only one respondent said that it was hard to understand.

Unlike the response of parents about the language, almost all the respondents were satisfied with the size of the booklet. About 98% respondents rated it as acceptable. None of them said that it was too big, or too small.

The font size used in the booklet was also considered appropriate by a majority of the respondents. Nearly all the respondents (96%) reported that the font size used in the booklet was acceptable. None of the respondents reported that it was too big, however, one respondent said that the font size used in the booklet was far too small.

The opinion of the respondents about the length of the booklet was not much different from their opinion about its size: about 94% of respondents reported that the length of the booklet was average, none of the respondents reported that it was too long, while only two respondents said that the length of the booklet was too short.

The colour scheme of the booklet was considered appropriate and acceptable by 92% respondents. None of the respondents rated it as too bright, but 6% of the respondents considered it dull.

Satisfaction of parents about content relevance and its usefulness was quite high. A majority of the respondents (90%) reported that the content was highly relevant to their needs, 8% rated it as relevant, while none of them rated it as irrelevant. In addition, 96% respondents reported that the content was very useful, 2% rated it as useful, while none of them rated it as useless.

Parents' opinion was also sought about the detail of the topics covered in the booklet. About 88% reported that the detail was very good, 8% ranked it as good , while only one respondent rated it as poor.

Table 7C: Comments and suggestions from the parents

Questions asked/characteristics	n (%)
Changes to the booklet suggested by parents:	
No change needed: It's just fine I think.	11 (22)
Write the topics in more detail.	2 (4)
Do you think it would be helpful to add more information to this booklet?	
Yes	5 (10)
No	45 (88)
Topics that should be added:	
No need to add anything else.	7 (14)
Topics are good, but more detail would be useful.	2 (4)
Add more strategies.	1 (2)
Don't add more to it. Make additional booklets: separate booklets can be developed on each topic.	1 (2)
Do you think it would be helpful to delete some information from this booklet?	
Yes	0 (0)
No	50 (98)
Topics that should be deleted	
It would not be good to delete any topic.	6 (12)
Would you find the booklet useful for anyone else in the	

family or child's school?	
Yes	46 (90)
No	2 (4)
Comments or suggestions:	
It is a very useful booklet	12 (24)
It is an excellent effort	3 (6)
There are no such booklets available in Pakistan	2 (4)
More work of this kind should be done	7 (14)
It would increase parents' understanding of autism	2 (4)
The suggestion section was and excellent part	2 (4)
Pictures should be added	1 (2)
CDs could also be developed: if something is shown in a real setting it would make it easier for parents to understand	1 (2)
The booklet was perfect for fathers who don't usually have much time as it covered essential information in a comprehensive manner. A detailed booklet would be more useful for mothers who spend more time with the child	1 (2)
This much is enough. The booklet would become very long if more information were to be added which would reduce its effectiveness	1 (2)
Such booklets for teachers and doctors should also be developed	1 (2)

In response to the question about changes to the booklet (if any) that parents would like to suggest, 22% reported that no change was needed. Two respondents, however, suggested that the topics should be written in more detail.

When parents were asked whether it would be helpful to add more information to the booklet, 88% reported that there was no need to add more information. Conversely, 10% respondents reported that it would be helpful to add more information, of whom two said that the topics were good, but adding more detail would be useful. One respondent suggested that more strategies should be added.

In response to the question about deleting some information, 98% responded that there was no need to delete any information from the booklet. Out of these, 12% added that it would not be good to delete any topic.

Participants also gave some general suggestions as well as. About 24% said that it was a very useful booklet, while 6% were of the opinion that it was an excellent effort. Two respondents added that the suggestion sections were the most useful parts of the booklet and two reported that the booklet would increase parent's understanding of autism.

About 14% of respondents suggested that more work of this kind should be done. One respondent added that, *'this will give an opportunity to the children with autism to pass their lives in a better way'.* In addition two of them reported that *'such booklets are not available in Pakistan, so more booklets of this type should be published'.* Three respondents suggested that booklets should be written on a child's problems and upbringing. In addition one respondent suggested that pictures should be added to the booklet. This respondent also suggested that, *'CDs should also be developed. If something is shown in a CD, such as an act in a real setting, it makes it much easier for parents to understand'.*

Suggestions about the length of the booklet varied slightly among respondents. One reported, *'as fathers usually don't have much time the booklet was perfect for them as it covered essential information in a brief and comprehensive manner. However, for mothers who spend much time with*

the child a more detailed booklet would be better'. Another respondent was of the opinion that the length of the booklet should not be changed, saying that, *'this much is sufficient and is quite comprehensive. The booklet would become very long if more information were to be added which would reduce its effectiveness'.*

Usefulness of the booklets for professionals or other members of the family was also identified by the parents. A majority of the respondents (90%) reported that the booklet would be useful for anyone else in the family or child's school. However, two respondents did not agree with the rest. In addition, one respondent suggested that such booklets should be developed for teachers and doctors. She complained about her child's teachers by reporting that, *'they do, whatever they want ... only the principal has some knowledge of the condition but the rest of the staff have no idea how to handle the child. Even we know better than them. Even we, the parents, are the ones who usually tell them to do this or avoid this. This is the situation'.'*

In summary, a majority of the respondents were quite satisfied with the contents and format of the booklet. They did not suggest many changes other than some minor ones.

7.3. Presentation of data collected from the professionals working with ASD children and their families

This part of the analysis contained a brief description of the results of the questionnaire completed by the professionals' target group to evaluate the effectiveness of the parent information and guidance booklet.

Demographic Characteristics of the sample

44 completed questionnaires were received, eight of which were completed by teachers, four by paediatricians, three by psychiatrists, two by educational advisors, two by school principals, two by speech and language therapists, one by a neurologist and one by an occupational therapist. The column of demographic information was left blank by the respondents in the remaining twenty one completed questionnaires

Table 7D: An overall evaluation of the booklet by the professionals

Questions asked/characteristics	n (%)
As an initial booklet given soon after diagnosis, the amount of information covered:	
It covers a reasonable amount of information	44 (100)
It does not cover a reasonable amount of information	0 (0)
Arrangement of information (format and organization):	
It makes sense	44 (100)
It does not make sense	0 (0)
Its suitability for parents of children with ASD living in Pakistan:	
It is suitable for them	42 (96)
It is not suitable for them	1 (2)
Suitable to some extent	1 (2)
The most useful topics covered in the booklet:	
All the topics/all of it	10 (23)
Problems faced, characteristics of children with autism and suggestions for improvement	6 (14)
Questions and answers about a child's behaviour	3 (7)
Brief suggestions on treatment approaches	1 (2)
Why should I give a label of autism to my child?	1 (2)
Least useful topics covered in the booklet:	
None/not a single topic was useless	16 (36)
Some topics were short	1 (2)
For a few topics, headings were sufficient. It did not require further elaboration	1 (2)

All the respondents (100%) reported that as an initial booklet given soon after diagnosis it covered a reasonable amount of information. One respondent, however, did not answer to the first three questions and ticked on all the options of the rating scale,therefore, that questionnaire was not included in the data analysis.

Surprisingly, 100% of respondents reported that the arrangement of information (format and organization) made sense.

It is important to note that the above were the first two questions throughout the present study in which all the respondents had the same opinion about an issue. This may reflect that participants were highly satisfied with the arrangement of information as well as the amount of information covered in the booklet.

The professionals' opinion was also sought about the suitability of the booklet for its audience. Nearly all the respondents (95%) reported that the booklet was suitable. Conversely, one reported that the booklet was not suitable for the parents, and one was of the opinion that the booklet was suitable for the target audience, but only to some extent.

The most useful topics covered in the booklet were also highlighted by the professionals who participated in the study. About 23% reported that all the topics covered in the booklet were very useful, while 14% reported that the problems faced by or characteristics of children with autism, and suggestions for improvement were the most useful topics covered. According to 7%, the questions and answers about a child's behaviour were very useful. One participant said that the brief on treatment approaches was a very useful topic, and one reported that the answer to the question 'Why should I give a label of autism to my child?' was the most useful topic covered.

When participants were asked to report the topics they found least useful in the booklet, 36% said that not a single topic was 'useless'. One participant added that the topics were, however, very short and brief, while one reported

that for a few topics a heading was sufficient and they did not require further elaboration.

Table 7E: Evaluating the booklet regarding its contents and format.

Please rate the booklet on:	n (%)
Language	
Easy to understand	33 (75)
Acceptable	11 (25)
Hard to understand	0 (0)
Size	
Far too small	0 (0)
Acceptable	44 (100)
Far too big	0 (0)
Font size	
Far too small	0 (0)
Acceptable	44 (100)
Far too big	0 (0)
Length	
Far too short	0 (0)
Acceptable	43 (98)
Far too long	1 (2)
Colour scheme	
Far too dull	4 (9)
Acceptable	39 (89)
Far too bright	0 (0)
Content relevance	
Very relevant	35 (80)
Relevant	11 (25)
Irrelevant	0 (0)
Content usefulness	
Very useful	41 (93)
Useful	3 (7)
Useless	0 (0)
Detail of topics	
Very good	36 (82)
Good	8 (18)
Poor	0 (0)

The professionals were also asked to rate the information and guidance booklet on its content and format.

Satisfaction of participants with the language of the booklet varied slightly from person to person. About 75% reported that the language used in the booklet was easy to understand, while 25% indicated that it was average.

Unlike the response of participants about the language used, all the respondents were satisfied with the size of the booklet as well as the font size. None of the respondents reported that it was too big or too small.

Opinion of the respondents about the length of the booklet was not much different from their opinion about its size. Nearly all the respondents (98%) reported that the length of the booklet was average. None of the respondents reported that it was too short, and only one said that the length of the booklet was too long.

The colour scheme of the booklet was considered appropriate and acceptable by 89% respondents. No respondents rated it as too bright, but 9% of the respondents considered it too dull.

Satisfaction of participants about content relevance and its usefulness was also high. About 93% reported that the content was very useful, 7% rated it as useful, while, none of them rated it as useless. Likewise, 80% reported that the content was highly relevant to respondents' needs, 25% rated it as

relevant, while none of them rated it as irrelevant. About 5% ticked two options: ‘highly relevant’, and ‘relevant’. Thus the percentage was slightly higher than 100.

Participants’ opinion was also sought about the detail of the topics covered in the booklet. Nearly 82% respondents reported that these were covered in very good detail, while 18% ranked them as having good detail.

Table 7F: Comments and suggestions

Questions asked/characteristics	n (%)
Changes to the booklet suggested by participants:	
No changes needed	9 (20)
An English version of the booklet should also be developed	1 (2)
Two booklets should be developed: a short one for those who need an overview of the disability, plus a detailed one for those who need to read about it in more detail	1 (2)
Do you think it would be helpful to add more information into this booklet?	
Yes	17 (39)
No	26 (59)
Missing data	1 (2)
Topics that should be added to the booklet:	
Use illustrations to elaborate an activity	4 (9)
Add some case histories	1 (2)
How to treat these children at home	1 (2)
Under ‘Incidence of autism’ references to facts and figures should be included	1 (2)
A brief history of autism	1 (2)
Do you think it would be helpful to delete some information from this booklet?	
Yes	1 (2)
No	42 (95)
Missing data	1 (2)
Topics that should be deleted from the booklet:	

Nothing should be deleted from the booklet	3 (7)
Reduce its length	1 (2)
Would you provide the booklet to parents of children with ASD or their family or school?	
Yes	42 (95)
No	0 (0)
Missing data	2 (5)
Comments or suggestions:	
It is very useful, comprehensive, to the point, relevant, or informative	12 (27)
It is an excellent effort	7 (16)
Booklets for teachers comprising techniques of teaching should also be published	3 (7)
This booklet would increase parent's understanding of autism	2 (5)
More work of this kind should be done	1 (2)
In every district there should be some focal person to whom an autistic child could be referred	1 (2)
Besides this booklet, such information should also be broadcast on TV, in newspapers, the internet, etc.	1 (2)
The booklet should be made easily accessible to the public. Spread it as widely as possible so that more people get to read it and more people with autism might be helped in this way.	1 (2)

Table 7F lists the overall comments and suggestions of the professionals about the parent information and guidance pack.

In response to the question about changes to the booklet, if any, that participants would like to suggest, 20% reported that no change was needed at all. One respondent however suggested that an English version of the booklet should also be developed. One teacher suggested that, *'two booklets should be developed. One booklet could be very short for those who need just an overview of the disability, while the other could contain more information for those who need to read about it in greater detail'.*

When respondents were asked whether it would be helpful to add more information to the booklet, 59% reported that there was no need to add any more. Conversely, 39% reported that it would be helpful to add more information. Of that number, four suggested that illustrations should be used to elaborate an activity. One respondent was of the opinion that some case studies of children should also be included. ‘How to treat children with autism at home’ was also a suggested topic by one participant. A minor change suggested by one of the participants was that under the heading ‘Incidence of autism’ reference to facts and figures should be made. One participant reported that a brief history of autism should be included.

In response to the question about deleting some information from the booklet, only one respondent reported that it would be helpfu, but 95% reported that there was no need to delete any information. One respondent suggested that the length of the booklet should be reduced.

Participants also gave some general suggestions as well as some comments about the booklet. About 27% said that it was a very useful booklet. Different participants used different words for it, such as ‘a comprehensive booklet’, while others considered it ‘relevant’ and ‘to the point’. Likewise, some said that it was very informative while others reported that it was very useful. In addition, 16% were of the opinion that it was an excellent effort. One paediatrician added, *‘this is a very good effort on your part and it should progress’.* Another reported, *‘your effort is a highly remarkable one ... Such*

an effort in our own language is greatly appreciated. May God reward you for it and enable you to continue this noble work'.

One respondent suggested that more work of this kind should be done, while two others added that the booklet would increase parents' understanding of autism. Usefulness of the booklet for parents, other members of the family and the child's school was also identified by the professionals who participated in the study. Nearly all the respondents (95%) reported that they would like to provide the booklet to parents of children with ASD, their family or school. Two respondents did not answer this question. In addition, three respondents suggested that such a booklet should be developed for use by teachers which could describe appropriate ways of teaching young children with autism.

Some general suggestions that may not directly link to the evaluation of the booklet were also given by the respondents and these may provide some guidelines for future work to be done in the field of autism in Pakistan. A paediatrician suggested that, *'in every district there should be some focal person to whom an autistic child could be referred'*, and one teacher added, *'besides this booklet such information should also be distributed through media such as TV, newspapers, the internet, etc.'* One psychiatrist suggested that, *'the booklet should be made easily accessible to the public. Distribute it as widely as possible so that more people will get to read it. Thus people with autism might be helped in this way'.*

In summary, participants showed satisfaction with the content and format of the booklet. No major changes to the booklet were suggested.

7.4. Summary of the results

The results presented above showed that the respondents were quite satisfied with the format and content of the booklet. The majority of the respondents supported the layout of the booklet as well as the content by considering it useful, relevant, and with sufficient detail. They were neither in the favour of deleting nor adding any topics.

However, four professionals and two parents suggested that illustrations should be added to elaborate an activity. One respondent recommended the addition of a brief history of autism, while one was of the opinion that at places in the booklet a source of information should also be quoted (e.g. references at the end of each section or paragraph indicating from where each piece of information came).

The recommendation of a few respondents about adding illustrations to elaborate an activity was considered initially. The purpose of adding pictures as well as the number was thought through carefully and indicated that adding a picture for each activity given to parents to manage their child's difficulties would not only increase the length of the booklet, but would also make it impractical. Moreover, the literature review and thematic analysis indicated that it was not a standard pattern of booklets written for parents of children with disabilities. Booklets and leaflets written for patients with a psychological disturbance, disability or problem included pictures for each

suggestion or symptom to aid understanding but the booklets written for parents and professionals omitted them. A few pictures were used in some but these did not appear to explain or elaborate each activity. This issue is still under consideration but the opinion of other parents and professionals should be sought on the issue before any change is made to the booklet. A modification made on the recommendation of only one or two respondents does not seem a valid choice.

The suggestion of a respondent about adding references or a history of autism was not considered for the booklet for many reasons. First, the literature review and thematic analysis (see chapter 6) indicated that it was not a standard pattern of booklet written for parents of children with disabilities. Second, it might have increased the length of the booklet or over-complicated it for a few parents who, according to the results of phase 4 (see chapter 5), recommended an easy to understand booklet with few pages. As discussed in chapter 5 a few professionals explained that parents living in Pakistan tended not to read any material if it were too long. The likelihood of a book being read would mainly depend on its length. Thus, to comply with the standard format of the booklets, accommodate low literacy and level of parents' understanding, and to make the booklet as brief as possible, this option was rejected.

The results of the study indicated that as an initial booklet given soon after diagnosis, the prototype covered a reasonable amount of information. Almost all the respondents reported that the arrangement of information (format and organization) made sense to them. In addition, a majority of the respondents

reported that the booklet was suitable for parents of children with ASD living in Pakistan. The results of the study also showed that the language used in the booklet was easy to understand, the size, length and colour scheme of the booklet as well as the size of the font used was quite appropriate. A few respondents however considered the colour scheme a bit dull, as anticipated. The literature review and thematic analysis (see chapter 6) indicated that the colour scheme which makes a text easily readable is often considered dull by the audience. Interestingly, the satisfaction of participants about the content of the booklet was quite high. They considered it highly relevant and useful.

In summary, the respondents were quite satisfied with the layout and content of the booklet and did not suggest any major changes.

7.5. Conclusion

This chapter presented results of the data collected from parent of children with ASD living in Pakistan and professionals working with these families to evaluate the effectiveness of the booklet designed as a result of this study. Conclusions and recommendations will be presented in the following chapter.

CHAPTER 8: CONCLUSIONS AND IMPLICATIONS

8.1. Introduction

This chapter begins with a reflection on the research methodology employed in the study followed by a presentation of key findings from the research in relation to the research questions. The chapter will conclude with recommendations as well as identifying areas for further research.

The layout of the chapter is as follows:

8.2. Summary of the research methods

8.3. Key findings

8.4. Conclusions

8.5. Limitations of the study

8.6. Recommendations

8.7. Further plans.

8.2. Summary and reflections on the method of research

8.2.1. Introduction

This study employed the knowledge-to-action (KTA) model of KT in order to examine the most appropriate method of knowledge translation for parents of children with ASD in the context of Pakistan. The rationale for this approach has been discussed in chapter 3 and the framework of the study on the basis of KTA was presented in chapter 4. This section provides a brief summary of

the method employed in the study and discusses some of the challenges that presented themselves during the course of the investigation.

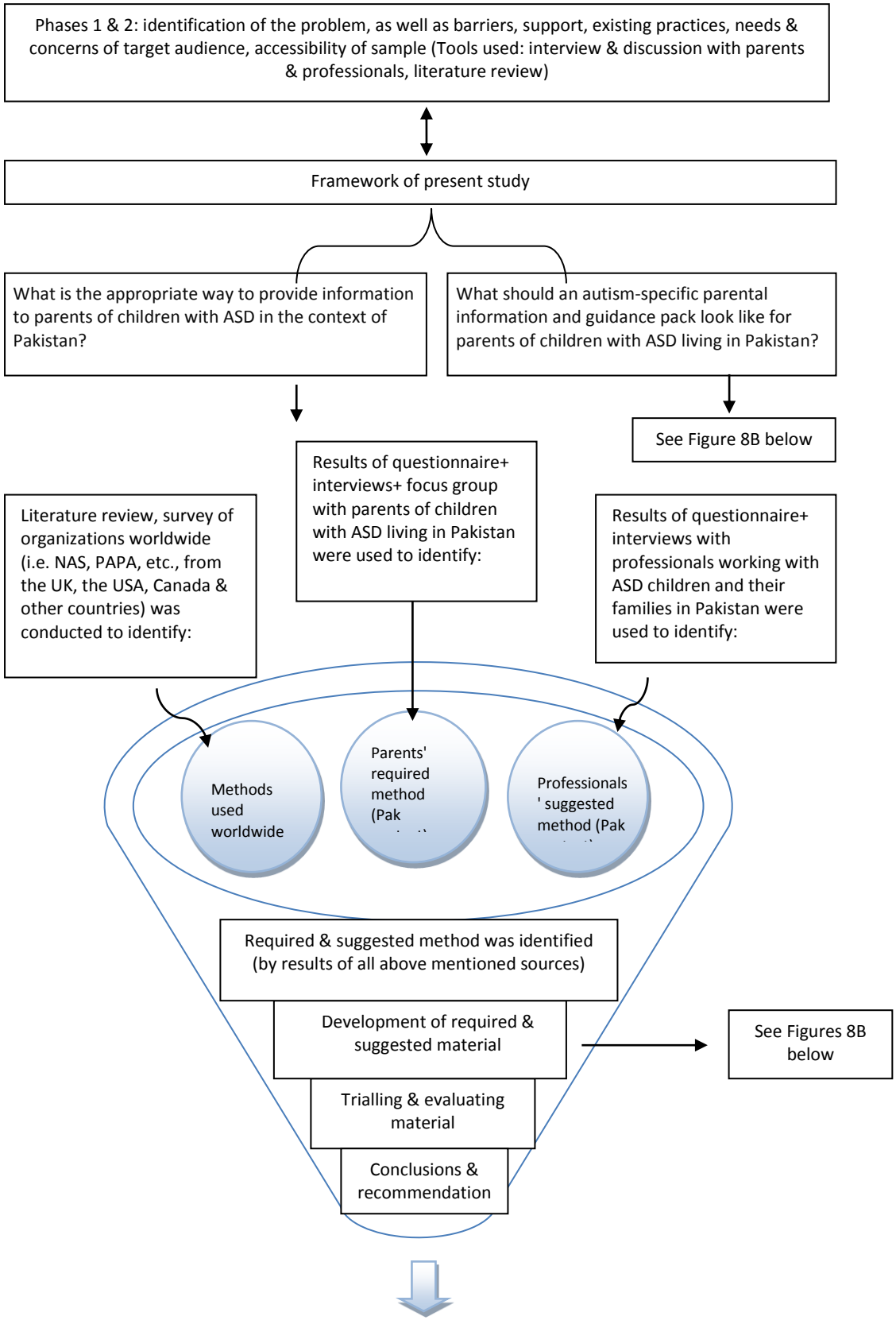
8.2.2. Summary of the research procedures adopted in the present study

In view of the nature of the intended study the KTA seemed appropriate as a framework as it provided guidelines for effective information transfer. Knowledge translation models are currently used in a number of healthcare settings worldwide, and are extensively used in preparing and disseminating guidelines and in developing support materials for nurses, healthcare professionals, patients and their caregivers (CIHR, 2012; Davis, 2005; Estabrooks et al. 2006; Logan and Graham, 1998; NCDDR, 2005; Sudsawad, 2007; WHO, 2006) (see chapter 3).

Following the process of KTA, the study encompassed several phases each of which informed the direction of the next. For example, data collected in phases 1 and 2 of the study informed phase 3 and the results of data collected at phase 4: step1 informed phase 4: step2.

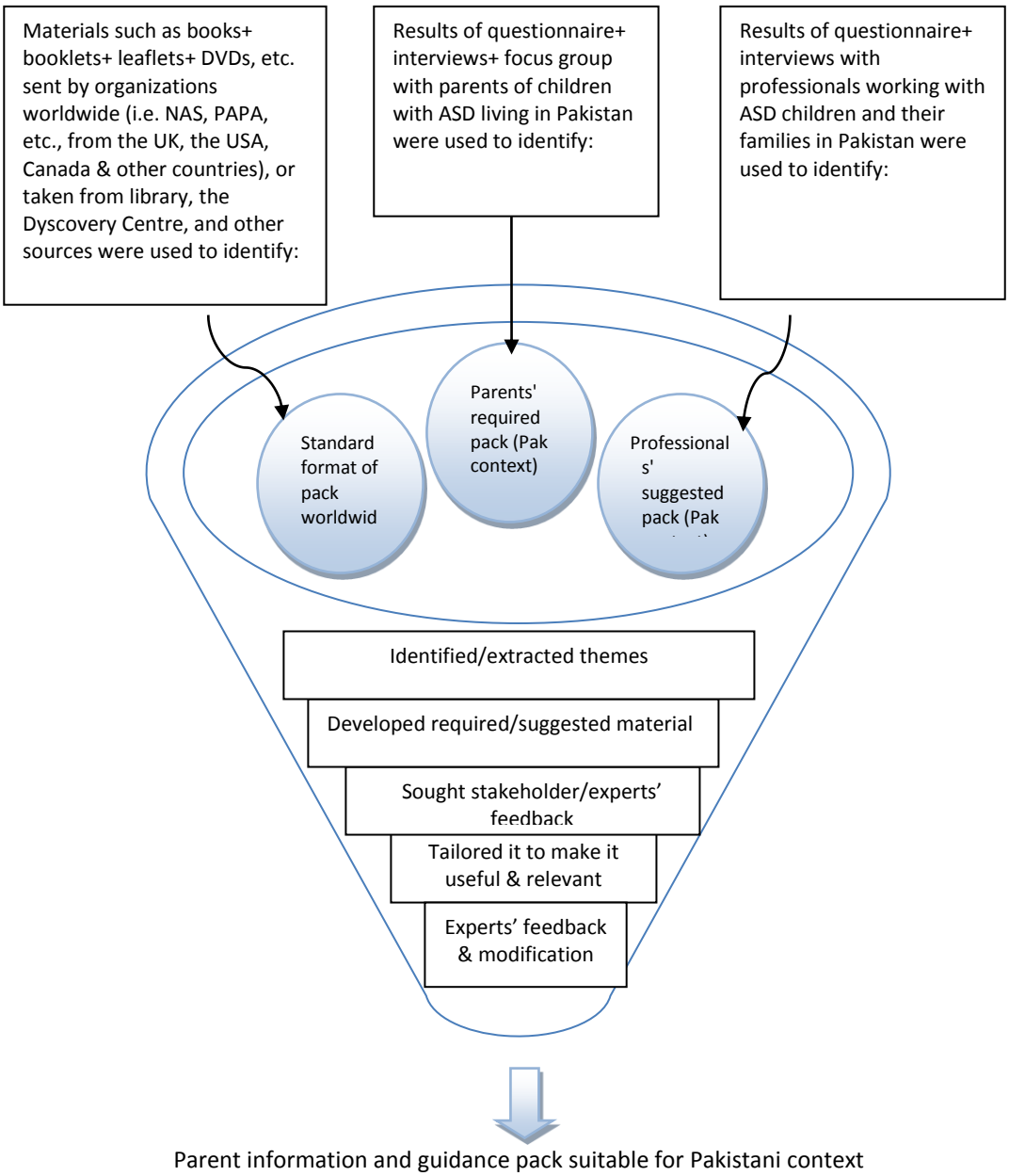
A brief description of the processes employed in the present study is presented below.

Figure 8A: Illustrative summary of the research processes employed in the present study



Appropriate method of knowledge translation for parents of children with ASD in the context of Pakistan

Figure 8B: Development of materials



The illustration is a representation of the processes to provide a conceptual overview, whereas in reality the process employed in the study was complex and dynamic as indicated by Graham et al. (2006) who developed the KTA model.

The above diagrams are an interpretation of the KTA model and differ from the ones presented by those who developed KTA in an attempt to represent the complexity of the knowledge transition process. The diagram of KTA presented in chapter 3 was used to highlight important aspects of knowledge translation rather than representing a rigid process to be followed exactly (as suggested by CIHR, 2012; Graham et al. 2006; Ilott et al. 2013; Sudsawad, 2007). Graham et al. (2006) indicated that for illustration purposes the knowledge translation process was divided into two concepts of 'knowledge creation' and 'action'. The phases included in their diagram were to give an idea of what should be included in the process. While describing the KT process and explaining their diagram and phases of each concept, Graham et al. (2006) mentioned that the actual process of knowledge translation is a very complex and dynamic one (see chapter 3).

Others have also noted this complexity. Ilott et al. (2013) indicated that knowledge creation cannot be separated from action. That is to say that the boundaries between the two concepts and the phases within them are permeable, i.e. the phases of knowledge creation are embedded in the phases of the action cycle (AHS, 2009; Campbell, 2010; CIHR, 2014; Graham et al. 2006; Sudsawad, 2007).

It was also noted in the present study that the process of knowledge translation was not simple or straightforward. Several phases of the action cycle and knowledge creation funnel occurred simultaneously, due to their

dependence upon and relevance to each other. For example, phases 2 to 4 of the action cycle and phase 1 of the knowledge creation funnel occurred simultaneously as they were about assessing the setting (needs of target audiences, local context and barriers) and identifying knowledge that might address the problem identified (see phase 4, step 1 in chapter 4). In addition, there was constant movement and interaction between the phases of knowledge creation and action. For example, phase 2 of the action cycle included phase 1 of knowledge creation: likewise, phase 5 of the action cycle included phases 2 and 3 of knowledge creation (see chapter 4).

A summary of the processes employed in the present study and steps taken at each stage was as follows:

- **Phase 1:** Identifying a problem that needs addressing – phase 1 of the KTA action cycle.

  Steps taken at this stage: The problem of the lack of any available information or guidance pack for parents of children with ASD was identified during discussions with parents and professionals working with these families (see phase 1 in chapter 4).

- **Phase 2:** Identifying the direction in which the study might evolve – phases 2-4 of the KTA action cycle.

  Steps taken at this stage: A literature review together with discussions with a sample of parents and professionals and a semi-structured interview with two professionals were conducted as a scoping exercise to identify the direction in which the intended study might evolve (see phase 2 in chapter 4).

- **Phase 3:** Modifying and finalizing the research proposal (see phase 3 in chapter 4).
- **Phase 4:** Identifying the appropriate methods of knowledge translation for the parents. This stage included phases 2 to 5 of the KTA action cycle, and phases 1 to 3 of the knowledge creation funnel. This stage was further divided into two steps.
    - **Phase 4, Step 1:** Collection of data required for material development and implementation – fulfilled phases 2 to 4 of the KTA action cycle and phase 1 of the knowledge creation funnel.

      Steps taken at this stage: Identification of relevant knowledge; materials were identified or collected from different sources including relevant books, booklets, DVDs, information and guidance packs for parents of children with ASD or other developmental disabilities, and notes or materials provided in training courses. Organisations working to support children with ASD and their families in the UK, USA, Canada, Australia, China, Japan, Bangladesh, India, UAE, the Netherlands and some other countries were contacted and asked to supply sample material on parent support used and/or developed by them, as well as to make some suggestions about the format of a parent information and guidance pack (see phase 4 in chapters 4 and 6).

      Assessment of setting i.e. needs of target audiences and local context. For this part of the study data were collected using

questionnaires, interviews and a focus group with parents of children with ASD and professionals working with these families (see phase 4 in chapters 4 and 5).

- **Phase 4, Step 2:** Development of parent information and guidance pack – fulfilled phase 5 of the KTA action cycle and phases 2 to 3 of the knowledge creation funnel.

  Steps taken at this stage: Thematic analysis of booklets designed for parents of children with disabilities by organisations working worldwide was conducted. Themes were extracted from the guides on writing simple material. In addition, findings were extracted from the data collected by using questionnaires, interviews and a focus group as in phase 4, step 1 above.

  The findings from this were used to develop the parent pack.

- **Phase 5:** Implementing, monitoring and evaluating parent information and guidance pack, and sustaining its use. This stage included phases 5 to 8 of the KTA action cycle.

  Steps taken at this stage: The pack was disseminated among the target group (see phase 5 in chapter 4).

  Following this process, two questionnaires were designed and administered to the parents and the professionals to evaluate the effectiveness of the parent pack (see phase 5 in chapter 4 and chapter 7).

  Finally, an informal telephone interview with a sample of the professional group was carried out to discuss the issues of

dissemination and sustainability of the pack. Further plans and recommendations are discussed later in this chapter.

8.2.3. Challenges faced

On the surface this study appears to be relatively simple, but it was made more complex by the many cultural barriers. Working on a project in a resource poor developing country posed plenty of challenges at different stages of the project. Some of the challenges were already anticipated by the researcher, while others presented themselves during the course of the investigation. In the main they were:

- Unavailability of any government or public list to identify parents or professionals. No governmental or public list could be located to identify or contact parents of ASD children and professionals working with these families in different cities of Pakistan. Therefore, selecting a sample, mailing questionnaires to parents and professionals or contacting them for interview was made very difficult.
- Access to population and engagement was challenging. The researcher had to travel to different cities to meet professionals for data collection as well as for piloting the booklet. Although the researcher was already aware that getting support from the professionals might be challenging it proved harder than expected.
- Agreeing convenient meeting times with professionals proved problematic in some cases.

- The distance travelled to different cities as well as to the homes of children with ASD to conduct interviews with parents was very expensive and time consuming.
- Restrictions on a female's mobility in Pakistan due to cultural norms made it challenging to approach the sample. Some of the researcher's family members accompanied her while travelling to other cities for data collection (see chapter 2 for further detail on mobility restrictions in Pakistan).
- A few questionnaires were completed by the parents but in some cases it was necessary to complete the questionnaire face to face (Robson, 2002) due to low levels of literacy or understanding. This also placed demands on resources such as time and money as it meant the researcher having to travel to different cities to meet the parents and assist them in completing the questionnaires. The characteristics of each sample group were established on the basis of discussion with the professionals who supplied the links to the parents. Therefore, where low levels of literacy or understanding were expected, face-to-face completion of questionnaires were carried out.
- It was hard to find authentic information on provisions made for ASDs and their families from government sources or published literature when data was not available even on the overall healthcare system in Pakistan (WHO, 2005). Therefore, data were collected on many essential issues which might not directly have related to the research topic but provided baseline information required to answer the main research question, and which could not be ignored while working on

knowledge translation strategies (see chapters 3 and 4). It increased the complexity of the process and resulted in the collection, analysis and interpretation of a spread of data.

- Problems associated with getting support in relation to translation of the booklet into Urdu also surprised the researcher. Initially, the Ministry of Education in Pakistan, heads of the Urdu department of some universities and those who were involved in literacy curriculum development were contacted by the researcher to get their assistance. Unfortunately no response from them was received by the researcher, therefore, utilizing other sources such as translating the prototype by working with college and university teachers to make the Urdu translation of the booklet more reliable was considered. The steps taken in this regard included a literature review, translation of the booklet, and piloting the booklet through two phases. In addition to considering the guidelines for writing simple material in any language for parents of children with disabilities prepared by organisations worldwide, guidelines provided by these agencies on translating the material from English to another language were also considered. A few booklets written in Urdu and published by Pakistani hospitals, or those written in English and translated into Urdu for the Pakistani population living in developed countries, were reviewed to identify a common pattern and style of writing for individuals with disabilities and their caregivers (see chapter 6). The booklet was then translated into Urdu by working with teachers of Urdu in colleges and universities in Pakistan. Once translated the booklet was piloted in two phases to

make it fit for purpose. Phase 1 comprised testing the Urdu version of the booklet in relation to its readability, appropriateness for the audience and accuracy of translation, while phase 2 tested the booklet in relation to its usefulness. Parents of children with disabilities, professionals working with such families and Urdu language teachers were all involved in the piloting phase (see chapter 6).

- The response rate for the evaluation part of the study was very low. It took months to get the completed questionnaires returned. Lack of co-operation from a few professionals also caused delay in distributing the questionnaires among the parents who visited them or the professionals who were contacted through them.

8.2.4. The way my position as a researcher might have influenced the data collected

Approaching the sample was challenging due to the cultural norms of general constraints on a female's mobility in Pakistan (see chapter 2). Some of my family members accompanied me while travelling to other cities for data collection. Drop off and pick up was provided by my family when I visited any participant's house or work place for interviews even in my own city.

On the other hand, my position as a female researcher might have had a positive influence on the data collected during my research. As discussed in chapter 2, gender segregation is a cultural practice in Pakistan, and many families prefer that women do not mix with men (Coleman, 2004; SDPI and JICA, 2008). Even in the health and education sector, female health

professionals, female teachers and educational institutions exclusively for girls are preferred by many (see chapter 2).

Additionally, in the case of population censuses, or any other national level research in which male researchers collect the data, usually male members of household provide information even about their female family members. Bari et al. (2000) reported that the labour force participation rates for women are grossly under-reported by the official sources of data due to problems with data collection such as male enumerators who get information regarding working women from the male members of the family.

If, for the present study, data were collected by a male researcher, participation of female respondents might have been low. In addition, data collected might have represented views from a certain group of people, e.g. affluent or broad-minded families who might have permitted females to participate in the study. It is, therefore, judged that for the present study data collection by a female researcher ensured an increased response rate and enriched data by giving an opportunity to women from different backgrounds to participate.

In cases where female respondents preferred interviews to be conducted at their home, the researcher visited their home. Again, the presence of a female researcher visiting the home and asking questions was preferable to their families; a male researcher would not have had such a level of family support. In addition, women talked freely and opened up to the female

researcher which might have been difficult in the case of data collected by a male researcher. Women feel comfortable talking to other women due to cultural practices, and their families do not mind them talking to another woman.

It is also important to note that in Pakistan, as in other patriarchal societies, the major restrictions are imposed on women, with limited or no restriction on men. Therefore, the gender of the researcher might have little or no influence on the response rate or the data collected for the present study from male respondents.

In addition, my position as a female researcher might have little or no influence on the data collected from professionals as they already work in unisex work places. However, my position as an academic researcher and lecturer at a public sector university might have had a positive influence on the data collected from the professionals and the response rate might have been higher when compared to that for a non-academic researcher. Participation in a research study in resource poor countries like Pakistan is very low when compared with developed countries like the UK. Even in the present study it was noticed by the researcher that when she contacted NAS and other organisations in the UK and other developed countries they responded instantly. But this is not the case in Pakistan. It takes weeks or months to get a response from a professional or an organisation. The response rate is very low and it is very difficult to get anyone engaged in the

research, an attitude which might be the result of people's lack of understanding about the importance of research.

In addition, my position as a native academic researcher might have had a positive influence on the accuracy of the data collected. If data had been collected by a non-academic or foreign researcher who would not be aware of real practices in the health and education system, there was a possibility that respondents might hide or misrepresent facts. But as the researcher was a professional herself and was aware of the system, considering her their colleague they opened up and talked freely. Even some of them during their interviews used words such as, 'as you would already know that co-operation is limited in our country', 'you know people do this', etc.

8.3. Key findings

The findings of the study are presented here by dividing it into the following sections:

Facilities or support services provided for ASD children

The results revealed that provision for children with ASD and their families were very limited in Pakistan. It was clear from this small sample that there was no provision of staff within any mainstream school for such children, nor was there any respite care for them. However, diagnostic facilities, a few special schools and therapy units were made available for children with ASD mainly in two provincial capitals, Lahore and Karachi. Parents living in other cities of the country, e.g. Multan, were referred to these cities for a formal

diagnosis. These parents, however, did have access to a psychologist, a neurologist, and a paediatrician in their area if they wished to consult them regarding their child's difficulties. In addition, the facilities and support services were usually provided by private sector or non-governmental organisations (NGOs).

Problems associated with getting a diagnosis of ASD in Pakistan

The results indicated that the process of getting a diagnosis of ASD was not well organised. The majority of the parents who participated in the study reported that they had consulted many professionals and visited many hospitals regarding their child's difficulties, but it took years to get a diagnosis that matched the child's symptoms. In some cases the time lag between first parental concern and diagnosis was reported to be seven years. Another concern reported by parents was confusion about their child's disability caused by the differing opinions of professionals which in a few cases did not match the child's symptoms.

A few parents reported that their child was misdiagnosed. The diagnostic labels wrongly given by relevant professionals before the child was diagnosed with ASD were: mentally retarded (MR), slow learner, hyperactive, and cerebral palsy (CP). In some cases, the professionals did not give any label to the child, but instead told the parents that the child was a slow learner, their IQ was low or they had some mental problem which could be cured by medicine. Parents also reported that the diagnosis given by one professional did not match the diagnosis given by another. One reason for

incorrect diagnosis may be the limited understanding of the condition among relevant professionals.

Information or training received (if any) by parents of ASD children for supporting their children

Findings revealed that there was no provision of home visits from any professional to help parents manage their child's behaviour. In addition, parents did not receive any guidance or training to understand and manage their child's behaviour (except one mother who reported having received TEACCH and another who received some other training).

A majority of the respondents did not receive or read any book, booklet, leaflet, or any other material on ASD and its management. Only a few parents had read books or had checked on websites to understand the condition better. A few parents had access to a discussion forum to talk with other parents about their child. In addition, a few parent got a chance to meet other parents at their child's therapy centre or school, which enabled them to share their problems and helped them understand to some extent the conditions associated with ASD.

Above all, the results appear to indicate that currently in this sample there was very limited provision for parents to gain information or training for supporting their child with ASD.

Concerns, wants and common attitude of the parents

The results of the study showed that the majority of the parents were most concerned about those areas that would be considered the child's core

symptoms of ASD, such as unusual or unwanted pattern of their child's behaviour, inappropriate or lack of language, inappropriate social interaction, and sensory difficulties of the child. Concerns about the child's education, a 'cure' for ASD, social stigma, problems with independent living skills (self-help skills), and the child's adulthood were also among the frequently reported by parents.

Common attitudes of parents indicated by a few professionals included lack of patience and motivation, pessimism about their child, confusion about the child's treatment and schooling, and non-cooperative behaviour of the child's father. Professionals also reported that a few parents were in the denial phase and a few others were looking for a 'magic stick' that might cure their child in no time. In addition, a professional added that a few parents wanted respite care, or preferably boarding school, for the child which might improve them and let the parents live a normal life. Parents' limited understanding and varying actions taken by them was also reported by the professionals. They described how a few parents were very harsh with their ASD children, while some were very lenient. It was reported that a few shouted, scolded and beat the child if they misbehaved; while others did not stop them from misbehaving (see chapter 5).

Need for a parent information and guidance pack

All the respondents urged the need for a comprehensive parent information and guidance pack.

Contents of a parent information and guidance pack

The results of the study indicated that a pack that covered all the essential information about ASD would be appropriate for the parent target group. Recommended contents were: suggestions on behaviour modification, communication, social interaction, independent living skills (self-help skills), and sensory difficulties. Other points to be included were information on a cure for ASD, the diverse symptoms of ASD, a brief introduction to ASD, its causes and intervention approaches, benefits of socialisation, and certain facts about autism.

Appropriate method of knowledge translation for the parents

Almost all the respondents suggested that the parent pack should take the form of a booklet. They were of the opinion that a DVD was not suitable to a Pakistani context for reasons included the problem of electricity in all areas of the country, low IT literacy among females in Pakistan, and unavailablity of computers at a few parents' homes due to their poverty.

In addition, a majority of the respondents were of the opinion that training at workshops was not a good choice for the Pakistani context compared with a booklet or a DVD due to limited time and money, a place to organise the training, availability of a resource person, suitable timing for parents, and accessibility to a large population. It was also highlighted by a few professionals that a general trend in Pakistan was the expectation for housewives to remain at home and in many cases it might become difficult for the mothers to attend training, thus, arranging workshops might only

reach a limited audience. The parents who opposed the idea of a training programme added that mothers could not spare the time for workshops or training as they had plenty of responsibilities including taking care of children and the family. Thus, in view of the limited resources and general trends of the population, the respondents recommended a booklet. They indicated that if the booklet were developed instead of training or workshops, it would be accessible to a larger group of people and could easily be distributed in different cities of Pakistan.

In common with the suggestion of parents, the professionals who participated in the study recommended that the booklet should be written in Urdu. All were of the opinion that parents would not be able to read or understand it if it were written in English. Respondents also indicated that the level of understanding of parents was quite low, thus the booklet should be easily readable and understandable. A few professionals explained that parents living in Pakistan tended not to read any material if it were too long, therefore, it should be brief, to the point and only a few pages long.

In summary, a brief, to the point and easily readable Urdu booklet was suggested by the majority of the respondents.

8.4. Conclusions

The results of the study indicated that the booklet was an appropriate method of knowledge translation for parents of children with ASD in the context of Pakistan.

The results seemed to be in harmony with the literature review which indicated that printed educational materials (PEMs) are widely used in dissemination strategies to improve knowledge, awareness, attitudes, skills, professional practice and patient outcomes (Bull et al. 2001; Giguere et al. 2012; Grimshaw et al. 2012). Booklets, leaflets and clinical guidelines appear to be among the most frequently adopted methods for disseminating information (Bero et al. 1998; Freemantle et al. 2000; Grimshaw et al. 2004). On the other hand, these are considered passive dissemination strategies which in a few studies showed little improvement in professionals' practice, whereas active dissemination strategies such as workshops showed better results in terms of improvement in practitioners' behaviour or clinical practice (Grimshaw and Eccles, 2008). Research did not oppose the use of printed material for parents of children with disabilities. Grimshaw et al. (2012, p.7) indicate that, 'printed educational materials are commonly used, have a relatively low cost and are generally feasible in most settings'.

Organisations working to support children with disabilities and their families tended to develop leaflets and booklets for patients as well as for their caregivers. Many examples were presented in chapter 6 of this dissertation such as Autism NI, CanCad, NAS, The Dyscovery Centre, etc. Out of many examples, the National Autistic Society in the UK organises parent workshops, home visits and other methods of transferring information to parents of children with ASD, but it did not ignore the use of printed educational material for parents, professionals or other interested parties.

Farmer et al. (2011, p.3) indicated that ‘given that PEMs are familiar, accessible, inexpensive, convenient to use and may lead to improvements in care, they could be a cost effective intervention within healthcare settings’.

In a resource poor country like Pakistan the cost effectiveness, feasibility and ease of use of printed educational material make it more suitable than other methods of disseminating information (Farmer et al. 2011; Grimshaw et al. 2012; Harmsworth et al. 2000; Law et al. 2004; Kreuter et al. 1999; Yale Centre for Clinical investigation, 2010). Such initiative in a resource poor setting is more practical and can be used on a large scale over the whole country whereas other methods, such as workshops, may pose plenty of challenges as well as being constrained by the budget (Majdzadeh et al. 2008; Santesso et al. 2006). Many resources are required to plan, execute, monitor, evaluate and sustainably implement such an initiative. This calls for a systematic and well organized governmental or private effort. Unfortunately, no such government or private dedicated mechanism is available in Pakistan to support children with autism and their families due to a high demand on resources and little awareness about the condition among the relevant authorities. Therefore, workshops or other similar initiatives appear difficult and impractical at the moment, while a booklet seems a more appropriate strategy.

Findings also revealed that workshops in each area would result in approaching a limited audience due to cultural constraints. Grimshaw and Eccles (2008) indicated that access to a research evidence source is a

common barrier to an effective knowledge transfer. Considering the cultural and geographic needs of the target audience is crucial in order to achieve effective information transfer (Glascoe et al. 1998; Graham and Logan, 2004; Grimshaw and Eccles, 2008; Ministries of Health and Education, New Zealand, 2008; Public Health Agency of Canada, 2011; Sudsawad, 2007). As discussed earlier, a general trend in Pakistan is that women, especially housewives, are not encouraged to go out freely. Although the rich, educated or elite class of the country might have a different approach, the majority of the population do not consider it desirable. Most families do not permit their women to go out alone even to visit a doctor (see chapter 2). In such cases where mothers would not be allowed to attend training, this method of information transfer would benefit only a fraction of society. A booklet on the other hand, could address this barrier and could have greater accessibility in such a setting.

Findings also revealed that using DVDs, websites, portals, forums and other IT to transfer information to parents would pose plenty of challenges in a Pakistani setting, even if these are designed in Urdu, the national language. All the parents of children with ASD and the professionals working with them who participated in the study were of the opinion that parents would not be able to read, understand or access information in English. Considering that accessing information in English would be not be possible for a majority of parents of children with ASD in Pakistan, designing websites, forums and even Windows (or any operating system) in Urdu is a greater challenge in itself.

In addition, all these media demand some skill on the part of the user as well as resources such as a computer which not all parents would have access to due to their poverty. Moreover, power failures of up to 20 hours a day in some areas of the country could restrict the number of users able to watch a DVD or use information on a website. IT literacy is very low among women in Pakistan. If there happened to be a computer and a generator to generate electricity at the time of load shedding in any house, there was no surety that the mother of the child would be able to operate the computer and see the DVD or access information on a website (NCDDR, 2005; O'Farrell et al. 1999; Westbrook and Boethel, 2005). Thus the importance of printed educational material in a Pakistani setting cannot be ignored.

However, the limitations of using booklets could not be ignored either. One possible barrier to using printed educational material could be low literacy or the limited level of understanding of the target audience (Grimshaw and Eccles, 2008) but this could be addressed by using simple easy-to-read material. Printed material could be tailored for an audience with more limited literacy skills through plain language, design and message development. Any attempt at simplifying the task would make the information available to a wider audience (Literacy Ontario Central South, Canada, 2010; SING, NHS Scotland, UK, 2011; Public Health Agency of Canada, 2011; US Department of Health and Human Services, 2010). Therefore, for the present study efforts were made to design an easy-to-read booklet by working with a range of stakeholders and by following the guidelines of organisations working

worldwide to develop materials for people with limited literacy or understanding, as well as for people with disabilities and their families (see chapter 6).

8.5. Limitations of the study

Several issues suggest that the results of the present study be interpreted with caution. These are presented below.

8.5.1. Participant recruitment

First, convenience sampling was used to select a sample for the study from all the provincial capitals and major cities of Pakistan, as no public lists could be located to identify or contact parents and professionals target groups. In addition, selecting a sample from each city of the country was not considered due to limited time, resources and lack of any public list. This made the results difficult to generalize to the entire population with certainty (Neuman, 2006; Sarantakos, 1998), but it can be considered a representative sample (Boudah, 2011; Gravetter and Forzano, 2011; Wood and Kerr, 2011) as the diagnosis facilities and other support services for ASDs appeared to be available only in the provincial capitals of the country at the time of starting this study. For that reason, parents either preferred to move there or had contact with professionals working in those cities. A sample of health and education professionals working in major cities of the country and two organisations (the PAMG, which was the only organisation working at national level to support families of children with ASD in Pakistan, and TIBM which was working to promote literacy in the country and education of

children with SEN) were contacted to request their support in locating as many parents of children with ASD and professionals working with these families as possible. Efforts were made to include all those identified by any source used (see chapter 4), however, a sample selected from each city of the country would have been more fully representative.

Secondly, to begin with data was collected mainly from members of PAMG at the stage of scoping the study, i.e. modifying and finalizing the research proposal, as the reality for this study of identifying potential participants was very challenging due to lack of any public list. Recruiting participants solely from support groups may introduce a sampling bias in the research (Duquin et al. 2008; Nijs et al. 2011). This is partly because people who attend support groups may have improved acceptance of their child's disability, may have more knowledge about it or may have strong opinions (Finn, 1999; Jefford, 2010; Noeres et al. 2011; Perron, 2002; Sherman, 2003; Ussher, et al. 2006; Van Uden-Kraan, et al. 2008; Van Uden-Kraan, et al. 2009; Wallerstein, 2006). Since participant recruitment may exert a significant influence on the outcome and generalizability of findings (Al-Shahi et al. 2005; Haring et al. 2008; Junghans et al. 2005; Moss and Von Ranson, 2006; Taylor et al. 2008; Wright et al. 2006), it has been recommended that studies should combine a variety of recruitment procedures or should recruit participants from mixed sources in order to increase the generalizability of study findings (Brierley et al. 2012; Duquin et al. 2008; Morley et al. 2009; Nijs et al. 2011; Norton et al. 2009; Parkes et al. 2006; Parkes et al. 2012; Völzke et al. 2008).

For the present study, if the participants had been recruited solely from support groups, it might have formed an unrepresentative sample and might have raised concerns to generalizability of the results. However, more than three-quarters of the parents and professionals who participated in the study were not members of support groups but merely identified with the help of these organisations (see chapter 4). For all the stages of the study except the modification of the research proposal, parents and professionals identified with the help of organisations or health and education professionals from the few major cities of the country were invited to take part in the study which may have formed a representative sample (Boudah, 2011; Brierley et al. 2012; Duquin et al. 2008; Gravetter and Forzano, 2011; Morley et al. 2009; Nijs et al. 2011; Norton et al. 2009; Parkes et al. 2006; Parkes et al. 2012; Völzke et al. 2008; Wood and Kerr, 2011), (see chapter 4).

In view of the type of data required in the study, participation from members of a support group may have yielded a positive influence on the data collected. As those who are involved in support groups are likely to be better informed about the disability and provisions for them (Finn, 1999; Jefford, 2010; Nijs et al. 2011; Noeres et al. 2011; Perron, 2002; Sherman, 2003; US National Institutes of Health, 2008; Ussher, et al. 2006; Van Uden-Kraan, et al. 2008; Van Uden-Kraan, et al. 2009; Wallerstein, 2006), their responses about services provided to children with ASD and their families in the country might have increased the correctness and richness of data.

8.5.2. Other limitations of the study

In some cases written notes were taken instead of audio recordings during the interview sessions. The majority of the interviews with parents, and almost half of the interviews with professionals were recorded, but some respondents refused consent to recording while consenting to note taking. As the accuracy of the note taking cannot be guaranteed, it may raise some challenges to the accuracy of the data.

Finally, the questionnaires were designed in English, the official language of Pakistan, as well as in Urdu, the national language, following the request of the parents and professionals contacted earlier in the questionnaire development phase. The researcher was aware that an Urdu version of the questionnaire would have been more accessible for all respondents, but it was likely that designing the questionnaire solely in Urdu would have resulted in a small return,as people might have considered the English version of enquiry a more professional and authentic survey. The researcher was also aware that providing a questionnaire to all respondents in one language would have appeared unanimous; but the requests, interests and needs of the respondents were among the important issues to be considered in real world research. Thus the questionnaire was administered in two languages to increase the response rate and to meet the requirement of a range of respondents having different interests, as well as levels of literacy and understanding.

8.6. Recommendations

8.6.1. Suggested recommendations for further research

Although, the present study has provided useful data which could be considered a stepping stone for other researchers, much work is needed in the field as awareness about the condition is at its initial stages in the country. In the present study data were collected on several issues which might not relate directly to the study but were essential in order to make an appropriate decision about the appropriate methods of knowledge translation for parents of children with ASD in the context of Pakistan. As information could not be identified on such issues through any authentic sources, due to unavailability or lack of published or government data, these issues were explored to some extent according to the requirement of the present study. However, there is a need for further exploration. For example, in the present study professionals working with ASD children were asked about the concerns reported by parents of these children. In a further study parents could be asked about their primary or secondary concerns and the parents' point of view could be compared with that of the professionals.

Findings also revealed that awareness about autism even among the relevant professionals is fairly limited. This issue needs investigating in greater detail before making a judgement, therefore, professionals' understanding of the condition could be another area of investigation. Also worthy of identification is what method would effectively transfer appropriate information to professionals working with ASD children and their families in Pakistan, as well as evaluating the impact of using the information on raising

awareness and increasing understanding of ASD in professional and parent groups.

Moreover, the results of the study revealed that the process of getting a diagnosis of ASD in Pakistan was lengthy, complicated and disorganised, as reported by parents. Further research in the area could explore this issue in depth through observation, obtaining information about existing practices and systems of care by involving relevant professionals and local authorities. Reasons behind the barriers to development which are making the diagnostic process complicated could be identified and recommendations made to resolve the issue.

8.6.2. Suggested recommendations for material development

The results of thematic analysis indicated that the reading age did not appear to be a consideration in writing booklets for parents of children with disabilities, although the language used in them appeared to be very simple, easy and straightforward. But reading age may need to be a recommendation for others especially if the reader is known to potentially have a lower level of literacy (see chapter 6).

8.6.3. Suggested recommendations for material translation

It was also found that reading ease did not appear to be a consideration in translating booklets from English to Urdu. In a few booklets the translated text seemed difficult to comprehend, while in some others certain terms were translated into Urdu when such terms might not be used even in the Urdu

speaking population. The following are a few recommendations for a culturally appropriate, natural sounding and easy-to-read translation:

- Literal translation should be avoided.
- Easy and common words should be used.
- If terms are to be translated into a target language, information should be collected in such terms as are in use in the target audience.
- The translator should be a skilled person and should be familiar with the cultural context and language pattern of the target audience.
- The issues considered while writing the original version of the material should also be considered while translating it. For example, the material should attract the readers' attention, should be easy to understand, etc. (see chapter 6).
- Proofreading should be arranged by an independent reviewer proficient in the target language.
- If possible, it should be piloted with the target audience.

8.6.4. General suggestions

- In future there is a need to further develop material for parents of children with ASD on different issues such as behaviour management, toilet training, handling sensory difficulty, etc.
- It is important when developing material for parents of children with ASD to consider possible barriers to knowledge use in addition to considering the requirements, concerns and needs of the target audience. These may include low literacy, limited level of understanding, low IT literacy even among literate mothers, access to population, cultural and structural constraints in planning and

executing workshops or other forms of transferring information to parents in the Pakistani context (see chapters 2, 5 and 6).

- Material should be developed in Urdu for greater accessibility and understanding.
- As awareness about the condition is in its initial stages, newspapers, magazines, TV or radio programmes could be used to increase awareness among communities.
- It would seem that there is a need for paediatricians, child psychiatrists and other relevant professionals in each city to be given in-service training to increase their understanding of the condition and to help them diagnose these children easily and efficiently.
- Booklets, leaflets, or other material should be designed for professionals who work with ASD children and their families to increase their awareness about the condition, its management approaches and other relevant issues.
- In addition to developing general materials for professionals, each group of professionals could be targeted separately. For example, materials could be developed for teachers comprising teaching techniques that might work well with ASD children.

8.7. Further plans

- Dissemination and sustainability are two important issues to be considered about the booklet designed as a result of the present study. Currently two NGOs have agreed to disseminate it among the parents, schools, or professionals who are in contact with them or

would contact them in future. In addition, support of the university the researcher is working in would also be sought to get assistance from the Ministry of Health for dissemination of the booklet. If achieving government support should prove difficult for the time being, organisations agreed to disseminate the booklets and a sample of health and education professionals working in major cities of the country would be asked to help in the dissemination process. At least a few copies of the booklets would be sent to each school for ASD children, hospital, and therapy unit and to a few professionals such as a paediatrician and child psychiatrist in each city (see chapter 6).

- An English version of the booklet which is already piloted would also be made available for those interested in reading it in English.
- It is also planned to translate the booklet into the regional languages of the country.
- For those who cannot read, an audio version is planned to be developed and made available.
- As parents of ASD children and professionals working in India were included in the present study, it is also planned that the booklet would be translated into Hindi. This initiative has already been taken and will be completed within a couple of months.
- As awareness is in its initial stages in the country, writing articles or editorials in newspapers and magazines might work as an initiative for others in addition to creating awareness about the condition. Therefore, it is planned to write on different issues such as the characteristics of ASD children, facts about ASD, a brief on

management approaches to creating awareness among communities as well as to transfer information to parents, problems associated with getting a diagnosis of ASD in Pakistan, provisions for ASD children and their families in Pakistan, concerns of parents to attract the attention of relevant researchers, professionals and local authorities towards issues that need addressing and require further research.

- Developing further materials including booklets for parents and professionals in collaboration with NGOs and universities is also another planned target to be achieved in the long term.

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APPENDICES

APPENDIX A: DSM-IV: Diagnostic criteria for Autistic Disorder (Autism)

A. A total of six (or more) items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3):

(1) Qualitative impairment in social interaction, as manifested by at least two of the following:

(a) Marked impairment in the use of multiple nonverbal behaviours such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction

(b) Failure to develop peer relationships appropriate to developmental level

(c) A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)

(d) Lack of social or emotional reciprocity

(2) Qualitative impairments in communication as manifested by at least one of the following:

(a) Delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)

(b) In individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others

(c) Stereotyped and repetitive use of language or idiosyncratic language

(d) Lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level

(3) Restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:

(a) Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus

(b) Apparently inflexible adherence to specific, nonfunctional routines or rituals

(c) Stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole body movements)

(d) Persistent preoccupation with parts of objects

B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as

used in social communication, or (3) symbolic or imaginative play.

C. The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder.

APPENDIX B: ICD-10: Diagnostic criteria for Childhood Autism (Autism)

The term ‘Childhood autism’ is used in ICD-10 to refer to children with autism. Their diagnostic criterion is presented in the following table.

F84.0 Childhood autism

A. Presence of abnormal or impaired development before the age of three years, in at least one out of the following areas:

(1) receptive or expressive language as used in social communication;
(2) the development of selective social attachments or of reciprocal social interaction;
(3) functional or symbolic play.

B. Qualitative abnormalities in reciprocal social interaction, manifest in at least one of the following areas:

(1) failure adequately to use eye-to-eye gaze, facial expression, body posture and gesture to regulate social interaction;
(2) failure to develop (in a manner appropriate to mental age, and despite ample opportunities) peer relationships that involve a mutual sharing of interests, activities and emotions;
(3) A lack of socio-emotional reciprocity as shown by an impaired or deviant response to other people's emotions; or lack of modulation of behaviour according to social context, or a weak integration of social, emotional and communicative behaviours.

C. Qualitative abnormalities in communication, manifest in at least two of the following areas:

(1) a delay in, or total lack of development of spoken language that is not accompanied by an attempt to compensate through the use of gesture or mime as alternative modes of communication (often preceded by a lack of communicative babbling);
(2) relative failure to initiate or sustain conversational interchange (at whatever level of language skills are present) in which there is reciprocal to and from responsiveness to the communications of the other person;
(3) stereotyped and repetitive use of language or idiosyncratic use of words or phrases;
(4) abnormalities in pitch, stress, rate, rhythm and intonation of speech;

D. Restricted, repetitive, and stereotyped patterns of behaviour, interests and activities, manifest in at least two of the following areas:

(1) an encompassing preoccupation with one or more stereotyped and restricted patterns of interest that are abnormal in content or focus; or one or more interests that are abnormal in their intensity and circumscribed nature although not abnormal in their content or focus.

(2) apparently compulsive adherence to specific, non-functional, routines or rituals;
(3) stereotyped and repetitive motor mannerisms that involve either hand or finger flapping or twisting, or complex whole body movements;
(4) preoccupations with part-objects or non-functional elements of play materials (such as their odour, the feel of their surface, or the noise or vibration that they generate);
(5) distress over changes in small, non-functional, details of the environment.

E. The clinical picture is not attributable to the other varieties of pervasive developmental disorder; specific developmental disorder of receptive language (F80.2) with secondary socio-emotional problems; reactive attachment disorder (F94.1) or disinhibited attachment disorder (F94.2); mental retardation (F70-F72) with some associated emotional or behavioural disorder; schizophrenia (F20) of unusually early onset; and Rett's syndrome (F84.2).

APPENDIX C: Sensory sensitivities: The possible presenting symptoms and signs.

Individuals with autism may experience a range of difficulties. In order to understand child's needs or certain behaviours, it is important for parents to gain an understanding of the potential problems children with autism may face (see Chapter 2). In addition to the sensory sensitivities presented in earlier chapters, the possible presenting symptoms and signs an individual with autism may also include:

- Balance and body awareness:
  - May rock, spin around, flap their hands
  - May stand too close to others
  - May bump into people
  - May have difficulties navigating rooms
  - May have difficulties avoiding obstructions
  - May have difficulties with fine motor skills/tasks (e.g. doing up buttons, tying shoe laces etc.)
- Sound:
  - May exhibit panic to specific sounds
  - May sometimes seems deaf
  - May dislike loud noises, crowded places
  - May dislike sudden, unexpected sounds (such as a dog barking etc.)
  - May dislike high-pitched or continuous noises
  - Some may like noisy places, and may bang doors and objects
  - May have difficulty filtering out unwanted sounds

- Vision/sight:
  - May play with light and reflections
  - May have problems with throwing and catching
  - May flick fingers before eyes
  - May have sensitivity to light or a particular level of illumination
  - May have difficulty filtering out unwanted movements or sights in a visually-busy environment
- Touch:
  - May not like to be touched
  - May have difficulty in brushing and washing hair, cutting nails, wearing clothes
  - May only like certain types of clothing
  - May not like anything on hands or feet
  - May hold others tightly
  - May not feel pain
  - May not feel extremes of temperature
  - May harm himself
  - May enjoy heavy objects on top of him
- Taste:
  - May like very spicy food
  - May eat everything (e.g. Soil, grass, materials)
  - May only like certain types of foods and flavours
- Smell:
  - May have no sense of smell and fail to notice extreme odours
  - May lick strong-smelling objects

- May have toileting problems
- May dislike perfumes and shampoos etc.

(Autism Spectrum Australia, 2002; Bogdashina, 2003; Crane et al. 2009; Janzen, 1996; Kern et al. 2006; Kern et al. 2007; Lennard-Brown, 2003; Nguyen, 2006; NAS, 2012; O'Neill and Jones, 1997; Wilkes, 2005).

APPENDIX D: Sample of country wise data base of the services provided for ASD children and their families by organizations working in developing countries.

In order to get an in depth understanding of the services provided for ASD children and their families in developing countries (i.e. countries with similar economic and cultural background, or countries in the same region) by organizations working to support children with ASD and their families, review of the websites of these organizations was carried out which is presented below.

BAHRAIN

One organization was found for this country. It was a non-governmental charity organization named: 'Bahrain Society for Children with Behavioral and Communication Difficulties', link: www.childbehavior.org

The services provided include: school for such children, short training programmes for parents and professionals. Intervention approaches used in the schools were ABA and TEACCH, with major focus on ABA.

However, detail about parent materials or training courses was not provided on their website.

BANGLADESH

During internet search, following organizations were identified. The first one was a government initiative, 2nd and 3rd were non-profit organizations, whereas the fourth one was established by parents of children with autism.

- **'Centre for Neurodevelopment and Autism in Children (CNAC)':**

  Link: http://www.cnacbangladesh.org/

  Services provided include: assessment, parent counselling, day care centre for children, therapies including OT, speech therapy and physiotherapy, training for doctors, teachers and therapists.

- **'Bangladesh ABA Centre for Autism':**

  Link: http://abacentreforautism.org/home.php .

  Services provided include: intense programme (ABA), assessment, training, residential services, etc.

  Parent training: 1 or 2 days trainings on different topics, such as toilet training, sleep problem, challenging behaviour, etc.

- **'Autistic children's welfare foundation':**

  Link: http://acwfbd.org/

  Services provided include: assessment and counselling.

  Information about parent materials or trainings was not provided on the website at the time of review.

- **'Society for the Welfare of Autistic Children (SWAC)':**

  Link: www.swacbd.org

  Services provided include: conferences and parent training. Due to technical problem with web site, further detail about parent training was not identified.

CHINA

During internet search, following organization were identified.

- 'China Autism Website':

Link: http://www.cautism.com/english/wzjj.htm

It is a government department's website.

Services provided include: Platform for parents to seek guidance. However information about parent materials or trainings was not provided on the website.

- **'Beijing Stars and Rain':**

  Link:

  http://www.autismchina.org/Default.aspx?alias=www.autismchina.org/English

  It is a non-governmental educational organization.

  Services provided include: Parent training, a preschool and a residential care. In schools, the preferred approach was ABA; in residential care TEACCH was considered; while detail of parent training is provided below.

  Parent training:

  Four courses are offered annually, where approximately 50 families from across China attend each course. Individualized educational programs for children with autism, ages 3-12 through an 11-week Parent-Training Course is provided. Teaching techniques are based on applied behaviour analysis (ABA). Skills are taught based on individual assessments and designed to meet the unique learning needs of each child. Areas taught range from learning readiness, self-care to academics and language. Parents also participate in all teaching activities.

- **'Beijing Association for Rehabilitation of Autistic Children (BARAC)':**

  Link: www.autism.com.cn or alternatively http://app.autism.com.cn/enterprise/jsp/special/autism.com.cn/index.jsp

  Website was not in English; therefore services provided by the organization were not identified.

EGYPT

- **'The ADVANCE Society (The Egyptian Society for Developing Skills of Children with Special Needs)':**

  Link: http://www.advance-society.org

  It is a non-profit organization.

  Services provided include: Education services for children, training programs, graduate degree programs for professionals and parents.

- **'The ADVANCE Center [run by Learning Resource Center]':**

  Link: http://www.lrcegypt.com/autism.html

  Services provided include: Workshops for parents and professionals, assessment, and school consultation.

GHANA

- **Autism Awareness Care and Training (AACT)':**

  Link: www.aact.org.gh

  The organization was formed by parents.

Services provided include: Daily care, public awareness campaigns, life-skills training, sensory integration therapy, training of caregivers, parents, family members, attendants and professionals, Art & Music therapy, field trips and extracurricular activities, and respite care for families.

INDIA

- **'Action For Autism (AFA)':**

  Link: http://www.autism-india.org/

  It is a national and non-profit organization.

  Services provided include: Assessment, intervention programmes, school, training centres, on job training to adults with ASD, social skill training, home support programmes, counselling, respite care, workshops, diploma in SE, publications, training manuals, and awareness raising.

  Parent training: A three month parent training programme called 'mother child programme'. 10 to 15 parents are trained together (with their children).

- **'The Autism Society Of India (ASI)':**

  Link: http://www.autismsocietyofindia.org/

  It is a national level organization. However apart from awareness campaign, details about its programmes were not found on website.

- **'Autism India':**

  Link: http://www.autismindia.org/

  Services provided include: A discussion forum for parents.

- **'Institute for Remedial Intervention services (IRIS)':**

  Link: http://www.autismindia.com/

  It is a non-profit organization.

  Services provided include: Consultancy and training provided for schools, parents and organizations. However, detail about trainings was not found on their website.

- **'Academy for Severe Handicaps and Autism – ASHA':**

  Link: http://www.ashaforautism.com/index1.html

  It is a non-profit organization.

  Services provided include: A day school for children, parent workshops and a few community awareness programmes.

INDONESIA

- **Masyarakat Peduli Autis Indonesia/Autism Society of Indonesia':**

  Link: http://www.autismindonesia.org/

  Website was not in English.

IRAN

- **'The Center for the Treatment of Autistic Disorders (CTAD)':**

  Link: http://ctad.ir/english/

  It is a welfare organization.

  Services provided include: An intensive Applied Behavior Analysis program, the Parent based therapeutic interventions (i.e. Little Bird program, Parent-Child Interaction therapy), PECS, speech therapy, occupational therapy, group social/cognitive training for high

functioning autistic children, music therapy, vitamin therapy, medication and nutritional interventions. Public awareness by talks, interviews and publications in public gathering, newspapers, magazines, TV and radio programs. Publication of a quarterly journal since 2011 which is the first magazine about autism in persian for general public.

- **'Bavar Iranian Autism Centre':**

  Link: http://www.bavariran.com/en/

  Services provided include: In centre, the preferred approach was ABA. The website was password protected. Therefore, detail about parent material or training was not found on their website.

MALAYSIA

- **'The Early Autism Project Malaysia':**

  Link: http://autismmalaysia.com/about-us/

  It is a non-profit organization.

  Services provided include: Assessment, parent training, intensive and individualized behavioral intervention for children with autism.

- **'The National Autism Society of Malaysia (Nasom)':**

  Link: http://www.nasom.com.my/

  It is a non-profit organization.

  Services provided include: Password protected. Installation required to log on to website.

- **'Malaysian Mental Health Association (MMHA)':**

  Link: www.mentalhealth.org.my

Services provided include: A Day Care Centre, organises public forums on mental health issues, provides support for carers of the mentally ill, runs family to family education groups, conducts a depression support group and advocates for the rights of the mentally ill.

UNITED ARAB EMIRATES

- **'Dubai Autism Center':**

  Link: http://www.dubaiautismcenter.ae/DACNews.htm

  It is a non-profit organization.

  Services provided include: Assessment, counselling, workshops, publications, school and a library.

- **ABA center for special needs':**

  Link: http://www.abacenter.org/aboutUs.htm

  It is a private, non-profit organization.

  Services provided include: School with major focus on ABA approach.

- **'The New England Center for Children'"**

  Link: http://www.necc.org/news/haad.asp

  Services provided include: School with major focus on ABA approach.

- **'Emirates Special Needs':**

  Link: http://www.emiratesspecialneeds.com/autism-pervasive-developmental-disorder.asp

  It is a non-profit organization.

Services provided: All sort of services for children with disabilities seemed to be provided by this organization. However no information was found on the website about parent materials or parent training.

APPENDIX E: Case studies

Case Study 1: Limited awareness of ASD among relevant professionals, and problems associated with getting a diagnosis of ASD in Pakistan.

The following is a case study of Child A (a 10-year old girl with ASD) as reported by her mother:

Child A suffered from developmental delays. She started speaking only one word 'mama' at the age of 2½ years. She started walking when she was one, but found it hard to maintain her balance. She was a bit weak and used to fall down often. Her mother reported:

> *All these things were quite confusing for us; therefore, we visited many doctors at different times. They told us that there was nothing wrong with the child, except that she was a bit weak. For that, we have been giving her vitamin syrup on doctor's advice. Besides that, we also enquired about her delayed speech. The doctor said that she'll start speaking when she'll be 'five' years old.*

The mother further told the interviewer that in-spite of using vitamin syrup on doctor's advice, the child's behaviour got worse with the passage of time. She reported:

> *Later on, my sister who is a doctor suggested that I should get a proper diagnosis for my daughter as she appears a special child.'*

The mother further reported that on her sister's advice she took the child to the best hospitals in the city and consulted many physicians including child

specialists, psychiatrists and neurologists at different times for a diagnosis. But the professionals kept on saying that there was nothing wrong with the child except that she was a slow learner. She further added that not a single professional told her that what was wrong with her child and why she behaved differently to other children.

> *I took her to different special schools for admission, but the owner of each school had a different opinion about her. Some said that she was a CP; some others were of the opinion that she was CP as well as ASD, while a few said that she was only ASD, and a few believed that she was a slow learner. A big problem was that everyone had a different opinion about her, and everyone diagnosed her differently. One school principal suggested that I should send her to a school in Lahore which was especially for CPs. I visited that school, but noticed that the children there had a lot of physical problems, whereas my daughter did not have any of those problems. Though sometimes she had problem maintaining balance she was able to do a lot of activities on her own. She was able to walk and was much better than those kids. I believed that she was not a CP case.*

The mother reported that finally the child was diagnosed with ASD at the age of seven.

<u>Case Study 2: Limited awareness of ASD among relevant professionals results in late diagnosis.</u>

The following is a case study of Child B (an 11-year old boy with ASD) as reported by his mother:

Child B who was diagnosed at the age of ten, went through similar situations as described in previous case study. His mother consulted many doctors at different times but not a single professional recognised the disability. She reported:

> *It took ten years to know that he is autistic. I knew it that he was special since he was few months old, but did not know which sort of disability he had ... and doctors were unable to diagnose. At the age of three, I took him for an IQ test. Even at that time the psychologist did not tell us that he was autistic.*

The mother consulted many neurologists as well but they did not recognise the disability either. She shared her pain that if her child had been diagnosed earlier, and if she had received any guidance on handling children with ASD, her son would have been in a better condition. She reported:

> *For ten years, I did not know what was wrong with him ... now it's quite late. Ten years in darkness!*

Case Study 3: Inappropriate decisions of parents due to lack of awareness about ASD (A lady was forced by her husband to abort the child, as they already had an ASD child)

One professional reported that:

a lady during her second pregnancy was being forced by her husband to abort the child. The lady was expecting her second child when the researcher conducted interviews with professionals. The lady, who was expecting, already had an eight-year old boy with autism. Her husband believed that if they had another child they might not be able to give proper

attention to their autistic boy and his behaviour would get worse. Thus he wanted his wife to abort the other child. But the mother was not willing to abort. She was quite sad, depressed and confused. She asked the opinion of the professional who told this story to the researcher. The professional suggested to her that she should not abort as the ASD child might learn from his typically developing siblings. He might imitate them and his behaviour might improve with the passage of time. But the professional told the researcher that the lady was being forced by her husband and in-laws to abort the child and had no choice but to abort.

Case study 4: Effect of ASD on family cohesion (a man who was willing to get rid of his ASD child, divorced his wife)

One professional reported that:

an educated and well-mannered person who was working in a very good position had an ASD child. Since the child was six-months old the man and his wife took their child to every place where any good treatment or therapy was available. If they heard about any treatment or therapy in any city of Pakistan they used to take their child there. The husband and wife had a very good relationship, and they both seemed very cooperative with each other. The man used to appreciate his wife and openly admitted that his wife was a very caring and nice lady.

For few months, the family did not visit me. When I enquired about it I got the news that the man had divorced his wife. The underlying reason was the willingness to get rid of the autistic child. Initially, he did not leave any stone

unturned to find treatment for the child, but when nothing worked and he found that child would remain special forever and would never be a typically developing child he wanted to get rid of the child. He knew that if he lived with his wife she wouldn't throw the child away. That's why he just divorced the lady, so that she might take the child with her, and he might have a peaceful life without a disabled child. Though he did not mention this reason to others, and just said, 'My wife doesn't cooperate with my family, that's why I have divorced her.'

Case study 5: positive attitude of parents about child's disability

One professional reported:

Few parents have a very optimistic approach. I know one doctor who had a baby girl with Down syndrome. She was their only daughter. Both the doctor and his wife were healthy, and were not overage either... but they had accepted it with open hearts. They said, ''it's all right. No matter what, but she is our daughter. We can't interfere in God's decisions'.

Case study 6: Extreme behaviour by parents

One professional reported that:

One highly educated man in a very good post has an 18-year old son with autism. When the ASD child was small he did not have many problems, his difficulties were quite mild. But his father is a very strict man. Perhaps due to his father's behaviour, the boy's behaviour has got much worse. Sometimes

the father heats an iron rod and beats or burns his son with it if the boy gets hyper or misbehaves. And sometimes he ties the boy in iron chains or rope.

The professional further reported that:

Once the boy's mother secretly complained to me about her husband and requested me to counsel her husband. I also enquired about it from the boy during a session. I then requested the parents to go out for a while and let me talk with the boy in the absence of parents. The boy had impaired communication and could not talk except for using a few words; but when I asked about his dad's behaviour, the boy started weeping. He told me, 'BABA MAARTA' (which means MY FATHER BEATS ME). I asked the boy's mum about it. She told me that if she tries to save the child, her husband beats her as well. Therefore, she usually stays out of it. I then counselled the boy's father. I asked him to remain gentle with the boy. But when the man went back home he beat his wife and son very badly. He got angry that they had spoken badly about him in front of others. The man was very short tempered. He used to get aggressive so quickly.

APPENDIX F: Semi structured parent interview schedule

Basic outline of interview conducted with parents of children with ASD
The interviews took an open and flexible approach. The questions were used as a guide but parents were encouraged to respond freely and to elaborate on other areas they felt were important to them.

Getting a diagnosis

1. What was the process of getting a diagnosis for your child?
2. Which professional(s) did you see for a diagnosis?
3. Did you face any problems with getting a diagnosis?
   If yes then, which sort of problems did you face?
4. On the basis of your experience of getting a diagnosis for your child with ASD, what would you like to say about the process of getting a diagnosis in Pakistan?

Provisions for children with ASD

5. Have any facility/support service been provided for your child?
6. If yes, then:
   i) Which facilities were provided for your child?
   ii) Who provided it?
   iii) How would you rate the services provided?
7. If you wish to see a professional regarding your child's difficulties, did you get access to that in your area?
8. If yes, then how would you rate the services provided by them?

Information/training received by parents for supporting their child

9. Did you receive any information/training for supporting your child?
10. If yes, then:
    i) Which sort of information/training did you receive?
    ii) Who provided it?
    iii) How did you find information/training received?

Recommendations for the 'parent information and guidance pack'

11. Is there any need for a parent information and guidance pack for parents of children with ASD living in Pakistan?
12. If yes, on the basis of your experience as a parent of a child with ASD:
    i) What would you like a parent information and guidance pack to contain?
    ii) What would you prefer the language of the pack to be?
    iii) What would you prefer the format of the pack to be?
    iv) If your suggested format is for a 'training/workshop', then what would you prefer the duration to be?

Any other comments/suggestion

13. Would you like to make any other comments/suggestion?

Thank you very much for your cooperation

APPENDIX G: Parent focus group schedule

Basic outline of focus group conducted with parents of children with ASD

The focus group took an open and flexible approach. The questions were used as a guide and basis for discussion. But parents were encouraged to respond freely and to elaborate on other areas they felt were important to them.

Getting a diagnosis

1. On the basis of your experience of getting a diagnosis for your child with ASD, what would you like to say about the process of getting a diagnosis in Pakistan?
2. Which professional(s) did you see for a diagnosis?
3. Did you face any problems with getting a diagnosis?
   If yes then, which sort of problems did you face?
4. Would you like to make any other comments about the diagnostic process?

Provisions for children with ASD

5. Have any facility/support service been provided for your child?
6. If yes, then:
   i) Which facilities were provided for your child?
   ii) Who provided it?
   iii) How would you rate the services provided?

Information/training received by parents for supporting their child

7. Did you receive any information/training for supporting your child?
8. If yes, then:
   i) Which sort of information/training did you receive?
   ii) Who provided it?
   iii) How did you find information/training received?

Recommendations for the 'parent information and guidance pack'

9. Is there any need for a parent information and guidance pack for parents of children with ASD living in Pakistan?
10. If yes, on the basis of your experience as a parent of a child with ASD:
    i) What would you like a parent information and guidance pack to contain?
    ii) What would you prefer the language of the pack to be?
    iii) What would you prefer the format of the pack to be?
    iv) If your suggested format is for a 'training/workshop', then what would you prefer the duration to be?

Any other comments/suggestion

11. Would you like to make any other comments/suggestion?

Thank you very much for your cooperation

APPENDIX H: Semi structured professional interview schedule

Basic outline of interview conducted with professionals working with children with ASD and their families in Pakistan

The interviews took an open and flexible approach. The questions were used as a guide but professionals were encouraged to respond freely and to elaborate on other areas they felt were important to them.

Concerns of parents of children with ASD

1. According to your experience as a professional working with children with ASD, which concerns are reported by the parents of children with ASD most often?

Recommendations for the 'parent information and guidance pack'

2. Is there any need for a parent information and guidance pack for parents of children with ASD living in Pakistan?
3. If yes, then on the basis of your experience as a professional working with children with ASD and their families:
   i) Which method of providing information to parents, do you think is appropriate to a Pakistani context?
   ii) What are the reasons for considering it appropriate for a Pakistani context?
   iii) If your suggested format is for a 'training/workshop', then what would you prefer the duration to be?
   iv) What would you prefer the language of the pack to be?
   v) What would you like a parent information and guidance pack to contain?
4. Do you think it would be helpful to have information divided into several packs?
5. If yes, then what do you think should be in each pack?

Any other comments/suggestion

6. Would you like to make any other comments/suggestion?

Thank you very much for your cooperation

APPENDIX I: Questionnaire for parents of children with ASD living in Pakistan – Consent Form, Questionnaire Information Sheet, and the Questionnaire.

University of Wales, Newport School of Education

Prifysgol Cymru, Casnewydd Ysgol Addysg

CANOLFAN DYSCOVERY CENTRE

Needs Assessment Form for the Development of a Home Support Package for the Parents of children with Autism Spectrum Disorder (ASD) living in Pakistan

Consent Form- Anonymous Data

I understand that my participation in this research project will involve completing a questionnaire about my child/children with ASD, which will take approximately 15/20 minutes of my time.

On the questions below, please tick 'YES' or 'NO'

1. **I understand that participation in this study is entirely voluntary and that I can withdraw from the study at anytime without giving reason.**

   YES ○
   NO ○

2. **I understand that I am free to ask any questions at any time (00447424548080, maria_sohaib@hotmail.com or dyscoverycentre@southwales.ac.uk).**

   YES ○
   NO ○

3. **I understand that the information provided by me will be held totally anonymously so that it is impossible to trace this information back to me individually.**

   YES ○
   NO ○

4. **I understand that in accordance with the Data Protection Act the information may be retained indefinitely.**

   YES ○
   NO ○

5. **I understand that I am free to withdraw my data or discuss concerns with the researcher.**

   YES ○
   NO ○

To request further information about the study or to discuss any concerns with the researcher please do not hesitate to contact on 00447424548080 or maria_sohaib@hotmail.com or dyscoverycentre@southwales.ac.uk.

To give your consent, please write your name below.

I agree to consent to participate in this study (please write your name here)

_____

University of Wales, Newport School of Education

Prifysgol Cymru, Casnewydd Ysgol Addysg

CANOLFAN DYSCOVERY CENTRE

Questionnaire Information Sheet

I would like to invite you to take part in a research study that is intended to:

Develop a Home Support Package for the Parents of children with Autism Spectrum Disorder (ASD) living in Pakistan.

Parents play a very important role in a child's life. They help the child learn ways to live a productive life in the community. Children with ASD may find it difficult to understand the world around them and may have difficulties with letting the world understand their perspective. This may lead to frustration for the child as well as for others.

The proposed study is intended to develop support materials to bridge the communication gap between parents and their child. These materials may be able to help prevent unwanted behaviours in the child; and may also empower parents to facilitate their child's social communication and elicit appropriate behaviour within the child's natural environment.

This survey is intended to find out:

a) the current status of the diagnostic process in Pakistan.
b) the current status of support services provided to parents.
c) the needs of parents regarding guidance and support services.

It would be extremely helpful if you could complete this form and return it in the reply-paid envelope. All information will be treated as confidential.

If you have any questions or comments please feel free to contact Maria Qureshi, 00447424548080 or email: maria_sohaib@hotmail.com or dyscoverycentre@southwales.ac.uk .

Thank you in advance for your time and help.

University of Wales, Newport School of Education

Prifysgol Cymru, Casnewydd Ysgol Addysg

CANOLFAN DYSCOVERY CENTRE

Needs Assessment Form for the Development of a Home Support Package for the Parents of children with Autism Spectrum Disorder (ASD) living in Pakistan

Section A: Background details: Getting a diagnosis

Child's Date of Birth: _____

Child's Gender: Boy ☐ Girl ☐

Questionnaire completed by: Mother ☐ Father ☐ Grand parent ☐ Other: _____

Address (City only): _____

Some information about how your child was diagnosed with Autism Spectrum Disorder (ASD)

1. Child's age at diagnosis: _____
2. Where diagnosed (City & name of clinic/hospital)? _____

   _____
3. Which professional(s) did you see for a diagnosis? (Please also put a number in each box according to order of meeting them, e.g. Paediatrician [3], Psychologist [1], Neurologist [2]).

   Paediatrician ☐ Occupational Therapist ☐ Speech and language therapist ☐

   Psychologist ☐ Neurologist ☐ Teacher ☐ Educational Advisor ☐

   Other (please state) _____
4. How old was your child when you first visit a professional regarding your child's difficulties?

   _____
5. How many times did you visit health or educational professionals before a diagnosis was given (approx.)? _____
6. Length of diagnostic process (from your first concern or visit to any professional till your child was diagnosed with autism): 0-3 Months ☐ 3-6 Months ☐ 6-9 Months ☐

   9-12 Months ☐ Any other time span (please specify) _____

7. Which professional(s) did you find very helpful in the diagnostic process and why?

_____

_____

8. Which of the following led you to take your child to a professional for diagnosis?

a) You read something about ASD ☐

b) You found your child's behaviour different from other children ☐

c) Somebody indicated that your child's behaviour was different from other children ☐

d) Developmental delay- speech/other ☐

e) Another child with ASD in the family ☐

f) Any other (please state) _____

9. Did you face any problems with getting a diagnosis? Yes ☐ No ☐

If yes then, please state what sort of problem you faced?

_____

_____

10. Any other comments about the diagnostic process?

_____

_____

Section B: Support Received

Some questions about the facilities and support services you received (if any)

Polite Note: Below are 2 sub-sections about facilities/support services (if any) provided for your child, If you received any of the following when your child was diagnosed with ASD, then please tick the column 'Yes' and also rate the service provided to you as well as tell about the authority that provided it.

B-1 Facilities and support services you received (if any)

Have the following facilities/services been provided for your child?					If yes, who provided the support services?	How would you rate the services provided?				
	Yes	No	Not needed	Which City		Very poor	Poor	Average	Good	Excellent
Special school for children with ASD										
Provision of staff within a normal school for your child										
Respite care										
If you wish to see a professional regarding your child's difficulties, did you get access to that in your area? 1) Speech and language therapist										
2) Psychologist										
3) Neurologist										
4) Occupational Therapist										
5) Physiotherapist										
6) Paediatrician										
7) Any other profession:										
Any other facility/service (Please specify):										

12. Did you have any opportunity to revisit the professional(s) who diagnosed your child in order to ask more questions? Yes☐ No ☐

If yes, what did you wish to know more about? _____

_____

B-2 Information/training you received (if any) for supporting your child

Have you received any of the following information/ training for supporting your child?	Yes	No	Not needed	Who provided it?	How would you rate it? Very poor	Poor	Average	Good	Excellent
Books, Leaflets or Booklets on ASD & its management									
DVDs on ASD & its management									
Website(s) on ASD & its management									
Access to a discussion forum to talk with other parents about your child									
Visit from a professional at your home to help you manage your child's behaviour									
Did you receive a training programme from the following to understand and manage better your child's behaviour:	Yes	No	Don't know						
1. TEACCH									
2. ABA									
3. SUN RISE									
4. PECS									
5. Any other training: __ _____ _____ _____									
Any other support (Please specify):									

Section C: Questions related recommendations for the content for the "parent information/training

14. On the basis of your experience as a parent of a child with ASD, what would you like a "parent information/training pack" for parents of children with ASD living in Pakistan to contain? Please tick the options you consider appropriate in the following table.

Suggested "parent information/training pack"		Rate according to the need to be included in the pack		
		Not important	Important	Very important
Content	**Brief introduction of ASD**			
	Causes of ASD			
	Brief introduction of Intervention approaches, (e.g. TEACCH, ABA, Sun-Rise, PECS, etc.)			
	Suggestions on promoting independent living skills (e.g. toileting, dressing, mealtimes, bath time, sleep routines, etc)			
	Suggestions on improving communication (e.g. flat or limited facial expression, inappropriate/no use of gestures, Repeat/ echoes words & phrases, Seems not to understand word meanings, use words literally, lack of useful language, problems with Initiating communication; inability to read the feelings of others, etc)			
	Suggestions on improving Social interaction (e.g. Unresponsive to people, no social smile, limited eye contact, social contact in unusual ways, does not play turn-taking games, no desire to interact with adults, or no desire to interact with children, etc)			
	Suggestions on behaviour modification (e.g. tantrums, aggression, self-injurious behaviour, repetitive use of a particular object such as the flicking of a rubber band or the twirling of string, plays the same game, resists changes, develops rigid routines, drifts aimlessly about, whirl, spin, bang head, bite wrist, exhibits strong/inflexible interests, etc)			
	Suggestions on handling sensory difficulties (e.g. lack of awareness of heat or cold or possible dangers; unusual/no response to pain; sensitivity to sounds, smells, touch; exhibits panic related to specific sounds, plays with lights & reflections, flicks fingers before eyes, strongly avoids certain clothes, foods, etc; attracted to specific patterns/textures, jump up & down, flap hands, etc)			

	Any other (please specify):			

		Tick here
Preferred Language	Urdu	
	English	
	Any other (please specify):	
Preferred Format	Booklets	
	DVDs	
	Website	
	Training/workshop	
	Any other (please specify):	
If your suggested format is for a 'training/workshop', then what would you prefer the **duration** to be?	1 day	
	2 days	
	3 days	
	Any other (please specify):	

Any other comments/ suggestion you would like to make: _____ _____

_____ _____

_____ _____

Thank you very much for your cooperation

APPENDIX J: Questionnaire for professionals working with ASD children and their families in Pakistan – Consent Form, Questionnaire Information Sheet, and the Questionnaire.

University of Wales, Newport School of Education

Prifysgol Cymru, Casnewydd Ysgol Addysg

CANOLFAN DYSCOVERY CENTRE

Survey for the content for the 'Parent Information/Training Pack' for Parents of children with Autism Spectrum Disorder (ASD)

Consent Form- Anonymous Data

I understand that my participation in this research project will involve completing a questionnaire about suggested pattern of Parent Information/Training Pack for parents of children with ASD, which will take approximately 3/5 minutes of my time.

On the questions below, please tick 'YES' or 'NO'

1. **I understand that participation in this study is entirely voluntary and that I can withdraw from the study at anytime without giving reason.**

   YES ○
   NO ○

2. **I understand that I am free to ask any questions at any time (00447424548080, maria_sohaib@hotmail.com or dyscoverycentre@southwales.ac.uk).**

   YES ○
   NO ○

3. **I understand that the information provided by me will be held totally anonymously so that it is impossible to trace this information back to me individually.**

   YES ○
   NO ○

4. **I understand that in accordance with the Data Protection Act the information may be retained indefinitely.**

   YES ○
   NO ○

5. **I understand that I am free to withdraw my data or discuss concerns with the researcher.**

   YES ○
   NO ○

To request further information about the study or to discuss any concerns with the researcher please do not hesitate to contact on 00447424548080 or maria_sohaib@hotmail.com or dyscoverycentre@southwales.ac.uk.

To give your consent, please write your name below.

I agree to consent to participate in this study (please write your name here)

_____

University of Wales, Newport
School of Education

Prifysgol Cymru, Casnewydd
Ysgol Addysg

CANOLFAN DYSCOVERY CENTRE

Questionnaire Information Sheet

AIM:
The purpose of this study is to consider the appropriate contents and format of a 'parent information/training pack' for Parents of children with Autism Spectrum Disorder (ASD).

RATIONALE FOR THE STUDY:
At the present time there are no specific 'parent information/training packs' in Pakistan. The intention of the study is to develop one after gaining an understanding of the parent's needs, gaining the professionals' consideration of the appropriate content and from the evidence base that supports the current understanding of ASD.

WHO IS BEING INVITED TO PARTICIPATE?
Professionals who have worked/are working with children with ASD.

WHAT DOES THE STUDY INVOLVE?
If you agree to participate in the study you will be asked to complete a questionnaire - this will take about 5 minutes. The questionnaire will ask for your recommendations for the content of a 'parent information or training pack' for parents of children with ASD.

HOW WILL MY INFORMATION BE USED?
The study and its methods have been approved by the Ethics Committee, University of Wales Newport. The study is being supervised by Professor Amanda Kirby. All information when published will remain anonymous and only the research team will be allowed to see your data. In the study you will be allocated a number so the information remains completely confidential.

If you would like to ask any questions or require more information please contact:

Maria Qureshi

The Dyscovery Centre
Felthorpe House
University of South Wales
Caerleon Campus, Lodge Road,
Caerleon
NP18 3QR
U.K.

maria_sohaib@hotmail.com or dyscoverycentre@southwales.ac.uk
07424548080

You are free to withdraw from the study at any time without giving reasons.

Thank you in advance for your time and help.

University of Wales, Newport School of Education

Prifysgol Cymru, Casnewydd Ysgol Addysg

CANOLFAN DYSCOVERY CENTRE

Survey for the contents for a 'parent information/training pack' for parents of children with Autism Spectrum Disorder (ASD)

Background details

Name (optional): _____

Profession: _____

Address (City only): _____ Country: _____

Questions related concerns of parents

1. According to your experience, which of the following concerns are reported by the parents of children with ASD most often? (Please tick the appropriate.)

   Almost never 1 2 3 4 5 Almost always

Concerns about the child with ASD	1	2	3	4	5
Inappropriate or no use of language					
Inappropriate or no social interaction					
Behaviour problems					
Sensory difficulties					
Independent living skills					
Stigma					
Disclosure					
Concerns about child's future life, e.g.: 1. Education					
2. Professional career					
3. Adulthood					
4. Marriage					
Any other concern reported (please specify):					

2. Any other comments you would like to make: _____

_____

_____

Questions related recommendations for the contents for a "parent information/training pack"

3. On the basis of your experience as a professional working with children with ASD, what would you like a "parent information/training pack" for parents of children with ASD to contain?
   Please rate the following items in order of importance for inclusion in the pack by ticking the appropriate box? Least important 1 2 3 4 5 Most important

Suggested 'parent information/ training pack'	1	2	3	4	5
Brief introduction of ASD					
Causes of ASD					
Suggestions on improving communication					
Suggestions on improving Social interaction					
Suggestions on behaviour modification					
Suggestions on handling sensory difficulties					
Suggestions on promoting independent living skills					
Brief introduction of intervention approaches, e.g.: 1. TEACCH					
2. ABA					
3. PECS					
4. AAC					
5. Any other (please specify):					
Any other content that you like to be added in the Pack (please specify):					

4. What would you prefer the **language** of the pack to be?
   Regional ☐ English ☐ Both ☐ Any other (please specify): _____

5. What would you prefer the **format** of the pack to be? (you can tick more than one)
   Leaflets ☐ Booklets ☐ Fact sheets ☐ Delivered directly as a training/workshop ☐
   Website ☐ DVDs ☐ Any other (please specify): _____
6. If your suggested format is for a 'training/ workshop', then what would you **prefer the duration** to be?
   Half day ☐ Evening session ☐ One day ☐ Two days ☐ Three days ☐
   Any other (please specify): _____

7. Do you think it would be helpful to have information divided into several packs?

   Yes ☐ No ☐

8. If your answer is yes to the above question, then what do you think should be in each pack?

   Pack 1: _____

   Pack 2: _____

   Pack 3: _____

   Pack 4: _____

9. Any other comments/ suggestion you would like to make: _____

   _____

   _____

Thank you very much for your cooperation

APPENDIX K: Questionnaire used with parents target group to evaluate the 'Parent Information and Guidance Booklet' – Consent Form, Questionnaire Information Sheet, and the Questionnaire.

University of Wales, Newport School of Education | Prifysgol Cymru, Casnewydd Ysgol Addysg | CANOLFAN DYSCOVERY CENTRE

Evaluation of the 'Parent Information and Guidance Booklet' for the Parents of children with Autism Spectrum Disorder (ASD) living in Pakistan

Consent Form- Anonymous Data

I understand that my participation in this research project will involve completing a questionnaire evaluating a 'Parent Information and Guidance Booklet designed for parents of children with ASD, which will take approximately 3-5 minutes of my time.

For the questions below, please tick 'YES' or 'NO'

11. **I understand that participation in this study is entirely voluntary and that I can withdraw from the study at anytime without giving reason.**

    YES ○
    NO ○

12. **I understand that I am free to ask questions at any time (00447424548080, 00923216302500 maria_sohaib@hotmail.com or dyscoverycentre@southwales.ac.uk).**

    YES ○
    NO ○

13. **I understand that the information provided by me will be held totally anonymously so that it is impossible to trace this information back to me individually.**

    YES ○
    NO ○

14. **I understand that in accordance with the Data Protection Act the information may be retained indefinitely.**

    YES ○
    NO ○

15. **I understand that I am free to withdraw my data or discuss concerns with the researcher.**

    YES ○
    NO ○

I agree to consent to participate in this study (please write your name below):

_____

To request further information about the study or to discuss any concerns with the researcher please do not hesitate to contact on 00923216302500, maria_sohaib@hotmail.com or dyscoverycentre@southwales.ac.uk.

University of Wales, Newport School of Education

Prifysgol Cymru, Casnewydd Ysgol Addysg

CANOLFAN DYSCOVERY CENTRE

Questionnaire Information Sheet

Dear Parent,

I would like to invite you to take part in a research study that is intended to **Develop Parent Information and Guidance Material for Parents of children with Autism Spectrum Disorder (ASD) living in Pakistan.**

A booklet has been designed (as a part of the study) which contains useful information about autism. It is likely to be given to the parents soon after their child's diagnosis. It is likely to bridge the communication gap between parents and their child with ASD, and may also help prevent unwanted behaviours in the child. This survey is intended to evaluate the effectiveness of the prototype.

The booklet and a questionnaire asking for your feedback and comments on the contents and format of the booklet are enclosed. It would be extremely helpful if you could complete this questionnaire which should take about 5 minutes, and return it in self-addressed, pre-paid envelope. The study has been approved by the Ethics Committee, University of Wales, Newport. All information will be treated as confidential.

If you have any questions or comments please feel free to contact Maria Qureshi, 00447424548080, 00923216302500 or email: maria_sohaib@hotmail.com or dyscoverycentre@southwales.ac.uk .

Yours sincerely,
Maria Qureshi

The Dyscovery Centre
Felthorpe House
University of South Wales
Caerleon Campus, Lodge Road,
Caerleon
NP18 3QR
U.K.

Thank you in advance for your time and help.

University of Wales, Newport School of Education

Prifysgol Cymru, Casnewydd Ysgol Addysg

CANOLFAN DYSCOVERY CENTRE

Evaluation Form for the 'Parent Information and Guidance Booklet' designed for Parents of children with Autism Spectrum Disorder (ASD) living in Pakistan

Background details

Name (optional): _____

Questionnaire completed by: Mother ☐ Father ☐ Grandparent ☐ Any other: _____

Address (City only): _____

Questions related format and organization of the booklet

1. As an initial booklet given soon after diagnosis, does it cover a reasonable amount of information?
   Yes ☐ No ☐

2. Does the arrangement of information (format and organization) make sense?
   Yes ☐ No ☐

3. Did you find this booklet helpful?
   Yes ☐ No ☐

4. If your answer is yes to the above question, in which way did it help you or your child?
   _____
   _____
   _____

5. **Please rate the booklet on:**

a. **Language:**
   Easy to understand ☐ Acceptable ☐ Hard to understand ☐

b. **Size:**
   Far too small ☐ Acceptable ☐ Far too big/large ☐

c. **Font size:**

Far too small	☐	Acceptable	☐	Far too big/large	☐

d. **Length:**

Far too short	☐	Acceptable	☐	Far too long	☐

e. **Colour scheme:**

Far too dull	☐	Acceptable	☐	Far too bright	☐

f. **Content relevance:**

Very relevant	☐	Relevant	☐	Irrelevant	☐

g. **Content usefulness:**

Very useful	☐	Useful	☐	Useless	☐

h. **Detail of topics:**

Very good detail	☐	Good detail	☐	Poor detail	☐

6. What were the most useful topics covered in the booklet?

vi. _____
vii. _____
viii. _____
ix. _____
x. _____

7. What did you find least useful in the booklet?

vi. _____
vii. _____
viii. _____
ix. _____
x. _____

8. Would you like to suggest any changes to the booklet? If yes, please provide details below:

_____
_____
_____

9. Do you think it would be helpful to add more information into this booklet?

Yes ☐ No ☐

10. If yes, what do you think should be added?

vi. _____

vii. _____

viii. _____

ix. _____

x. _____

11. Do you think it would be helpful to delete some information from this booklet?

Yes ☐ No ☐

12. If yes, what do you think should be deleted?

vi. _____

vii. _____

viii. _____

ix. _____

x. _____

13. Would you find the booklet useful for anyone else in the family or child's school?

Yes ☐ No ☐

14. Any other comments or suggestions you would like to make:

_____

_____

_____

Thank you very much for your cooperation

APPENDIX L: Questionnaire used with professionals target group to evaluate the 'Parent Information and Guidance Booklet' – Consent Form, Questionnaire Information Sheet, and the Questionnaire.

University of Wales, Newport School of Education

Prifysgol Cymru, Casnewydd Ysgol Addysg

CANOLFAN DYSCOVERY CENTRE

Evaluation of the 'Parent Information and Guidance Booklet' for the Parents of children with Autism Spectrum Disorder (ASD) living in Pakistan

Consent Form- Anonymous Data

I understand that my participation in this research project will involve completing a questionnaire evaluating a 'Parent Information and Guidance Booklet' designed for parents of children with ASD, which will take approximately 3-5 minutes of my time.

For the questions below, please tick 'YES' or 'NO'

6. **I understand that participation in this study is entirely voluntary and that I can withdraw from the study at anytime without giving reason.**

   YES ○
   NO ○

7. **I understand that I am free to ask questions at any time (00447424548080, 00923216302500 maria_sohaib@hotmail.com or dyscoverycentre@southwales.ac.uk).**

   YES ○
   NO ○

8. **I understand that the information provided by me will be held totally anonymously so that it is impossible to trace this information back to me individually.**

   YES ○
   NO ○

9. **I understand that in accordance with the Data Protection Act the information may be retained indefinitely.**

   YES ○
   NO ○

10. **I understand that I am free to withdraw my data or discuss concerns with the researcher.**

    YES ○
    NO ○

I agree to consent to participate in this study (please write your name below):

_____

To request further information about the study or to discuss any concerns with the researcher please do not hesitate to contact on 00923216302500, maria_sohaib@hotmail.com or dyscoverycentre@southwales.ac.uk.

University of Wales, Newport School of Education

Prifysgol Cymru, Casnewydd Ysgol Addysg

CANOLFAN DYSCOVERY CENTRE

Questionnaire Information Sheet

AIM:

The purpose of this survey is the evaluation of a 'Parent Information and Guidance Booklet' that is designed for Parents of children with Autism Spectrum Disorder (ASD) living in Pakistan.

RATIONALE FOR THE STUDY:

At the present time there are no specific need oriented 'Parent Information and Guidance Booklets' in Urdu for parents of children with ASD living in Pakistan. A booklet has been designed (as a part of the study) that incorporates an understanding of parents' needs, the professionals' consideration of appropriate content and the evidence base that supports the current understanding of ASD. The booklet is likely to be given to the parents soon after their child's diagnosis, and contains brief and useful information about autism. The intention of the current survey is to find out the effectiveness of the prototype.

WHO IS BEING INVITED TO PARTICIPATE?

Professionals who have worked or are working with ASD children and their families in Pakistan.

WHAT DOES THE STUDY INVOLVE?

If you agree to participate in the study you will be asked to complete a questionnaire which will take about 3 minutes, and return it in self-addressed, pre-paid envelope. The questionnaire will ask for your feedback and comments on the contents and format of the enclosed 'Parent Information and Guidance Booklet' designed for parents of children with ASD living in Pakistan.

HOW WILL MY INFORMATION BE USED?

The study has been approved by the Ethics Committee, University of Wales, Newport. The study is being supervised by Professor Amanda Kirby. All information when published will remain anonymous and only the research team will be allowed to see your data. In the study you will be allocated a number so the information remains completely confidential.

If you would like to ask any questions or require more information please contact:

Maria Qureshi
The Dyscovery Centre
Felthorpe House
University of South Wales
Caerleon Campus, Lodge Road,
Caerleon
NP18 3QR
U.K.

maria_sohaib@hotmail.com or dyscoverycentre@southwales.ac.uk
00447424548080, 00923216302500.

Thank you in advance for your time and help.

University of Wales, Newport School of Education

Prifysgol Cymru, Casnewydd Ysgol Addysg

CANOLFAN DYSCOVERY CENTRE

Evaluation Form for the 'Parent Information and Guidance Booklet' designed for Parents of children with Autism Spectrum Disorder (ASD) living in Pakistan

Background details

Name (optional): _____

Profession: _____

Address (City only): _____

Questions related format and organization of the booklet

1. As an initial booklet given soon after diagnosis, does it cover a reasonable amount of information?

   Yes ☐ No ☐

2. According to your experience, is it suitable for parents of children with ASD?

   Yes ☐ No ☐

3. Does the arrangement of information (format and organization) make sense?

   Yes ☐ No ☐

4. **Please rate the booklet on:**

a) Language:

Easy to understand ☐ Acceptable ☐ Hard to understand ☐

b) Size:

Far too small ☐ Acceptable ☐ Far too big/large ☐

c) Font size:

Far too small ☐ Acceptable ☐ Far too big/large ☐

d) Length:

Far too short ☐ Acceptable ☐ Far too long ☐

e) Colour scheme:

Far too dull ☐ Acceptable ☐ Far too bright ☐

f) Content relevance:

Very relevant ☐ Relevant ☐ Irrelevant ☐

g) Content usefulness:

Very useful ☐ Useful ☐ Useless ☐

h) Detail of topics:

Very good detail ☐ Good detail ☐ Poor detail ☐

5. What were the most useful topics covered in the booklet?

i. _____
ii. _____
iii. _____
iv. _____
v. _____

6. What did you find least useful in the booklet?

i. _____
ii. _____
iii. _____
iv. _____
v. _____

7. Would you like to suggest any changes to the booklet? If yes, please provide details below:

_____
_____
_____

8. Do you think it would be helpful to add more information into this booklet?

Yes ☐ No ☐

9. If yes, what do you think should be added?

i. _____
ii. _____
iii. _____
iv. _____
v. _____

10. Do you think it would be helpful to delete some information from this booklet?

Yes ☐ No ☐

11. If yes, what do you think should be deleted?

i. _____

ii. _____

iii. _____

iv. _____

v. _____

12. Would you provide the booklet to parents of children with ASD or their family or school?

Yes ☐ No ☐

13. Any other comments or suggestions you would like to make:

_____

_____

_____

Thank you very much for your cooperation

APPENDIX M: Urdu version of the questionnaire used with parents target group to evaluate the 'Parent Information and Guidance Booklet' –Consent Form, Questionnaire Information Sheet, and the Questionnaire.

University of Wales, Newport
Newport School of Education
Prifysgol Cymru, Casnewydd
Ysgol Addysg Casnewydd

ANOLFAN DYSCOVERY CENTRE

سروے کا موضوع : آٹزم میں مبتلاء بچو ں کے والدین کے لیے معلوماتی وتربیتی کتابچے کا جائزہ

اجازت نامہ

مجھے معلوم ہے کہ اس تحقیق میں میری شمولیت کا مقصد ایک سوالنامے کو پر کرنا ہے جسے پر کرنے میں تقریباً تین سے پانچ منٹ کا وقت لگے گا۔ یہ سوالنامہ ایک معلوماتی وتربیتی کتابچے کا جائزہ لینے کے لیے بنایا گیا ہے۔ جو آٹزم میں مبتلاء بچوں کے والدین کی تربیت کے لیے تیار کیا گیا ہے۔

مندرجہ ذیل سوالات کے جواب میں ہاں یا نہیں پر نشان لگائیں۔

1۔ مجھے معلوم ہے کہ اس تحقیق میں میری شمولیت رضا کارانہ ہے اور میں کسی بھی وقت بغیر وجہ بتائے اس میں شمولیت سے انکار کرسکتا/ سکتی ہوں۔ (ہاں) / (نہیں)

2۔ مجھے معلوم ہے کہ میں کسی بھی وقت تحقیق سے متعلق سوال پوچھ سکتا/ سکتی ہوں۔ (ہاں) / (نہیں)

3۔ مجھے معلوم ہے کہ میری طرف سے فراہم کی گئی معلومات کو صیغہ راز میں رکھا جائے گا۔ (ہاں) / (نہیں)

4۔ مجھے معلوم ہے کہ معلومات کے تحفظ کے قانون کے پیش نظر معلومات کو ہمیشہ برقرار رکھا جاسکتا ہے۔ (ہاں) / (نہیں)

5۔ مجھے معلوم ہے کہ میں اپنی فراہم کردہ معلومات کی منسوخی یا کسی بھی قسم کے خدشات پر محقق سے بات چیت کرسکتا/ سکتی ہوں۔ (ہاں) / (نہیں)

اگر آپ اس تحقیق میں حصہ لیے پر رضامند ہیں تو مندرجہ ذیل لائن پر اپنا نام درج کریں۔

میں اس تحقیق میں حصہ لینے پر رضامند ہوں۔

نام:_____

تحقیق سے متعلق مزید معلومات کے حصول کے لیے محقق سے فون یا ای میل پر رابطہ کیا جاسکتا ہے۔

فون نمبر: 00923216302500, 00447424548080

ای میل نمبر: maria_sohaib@hotmail.com, dyscoverycentre@southwales.ac.uk

(آپ کے تعاون کا شکریہ)

University of Wales, Newport
Newport School of Education

Prifysgol Cymru, Casnewydd
Ysgol Addysg Casnewydd

NOLFAN DYSCOVERY CENTRE

سوالنامے کے بارے میں معلومات

میں آپ کو ایک تحقیق میں شمولیت کی دعوت دیتی ہوں جس کا مقصد ''آٹزم میں مبتلاء بچوں کے والدین کے لیے ایک معلوماتی وتربیتی کتابچے'' کی تیاری ہے۔ والدین بچے کی زندگی میں اہم کردار ادا کرتے ہیں وہ بچے کو معاشرے میں رہنے کے طور طریقے سکھاتے ہیں اور اسے ایک اچھی زندگی گزارنے کے قابل بناتے ہیں آٹزم میں مبتلاء بچے میل جول اور گفتگو کے حوالے سے کئی مسائل کا شکار ہوتے ہیں۔ اس لیے انہیں لوگوں کو سمجھنے میں بھی دشواری ہوتی ہے اور دوسروں کو اپنی بات سمجھانے میں بھی۔ معاشرے میں رہنے کے طور طریقوں کو سمجھے میں ناکامی، آٹزم میں مبتلاء بچوں کو معاشرے کے لیے ناقابل قبول بنا سکتی ہے۔

مجوزہ تحقیق کا بنیادی مقصد والدین اور بچے کے درمیان بات چیت کے خلاء اور سمجھنے سمجھانے کی دشواری کو کم کرنا ہے۔ اس تحقیق کا مقصد والدین کے لیے ایسے معلوماتی وتربیتی مواد تیار کرنا ہے جس کی مدد سے وہ بچے کو معاشرے میں رہنے کے قابل بنا سکیں۔ مواد کی تیاری کے ضمن میں آٹزم میں مبتلاء بچوں کے والدین کے لیے ایک معلوماتی وتربیتی کتابچہ تیار کیا گیا ہے۔ اس کتابچے کی افادیت کا جائزہ لینے کے لیے مندرجہ ذیل سوالنامہ تیار کیا گیا ہے آپ کی رائے اس ضمن میں بہت اہم کردار ادا کر سکتی ہے۔ مندرجہ ذیل سوالنامے کو پُر کر کے جوابی لفافے میں ڈال کر پوسٹ کر دیجئے۔ آپ کی فراہم کردہ معلومات کو صیغہ راز میں رکھا جائے گا۔

اگر آپ کو کوئی بھی سوال پوچھنا ہو یا رائے دینی ہو تو ماریہ قریشی سے رابطہ کریں۔

فون نمبر: 00923216302500, 00447424548080

ای میل نمبر: maria_sohaib@hotmail.com, dyscoverycentre@southwales.ac.uk

(آپ کے تعاون کا شکریہ)

University of Wales, Newport
Newport School of Education
Prifysgol Cymru, Casnewydd
Ysgol Addysg Casnewydd

CANOLFAN DYSCOVERY CENTRE

سوال نامہ برائے آٹزم میں مبتلاء بچوں کے والدین کے لیے معلوماتی و تربیتی کتابچہ

بنیادی معلومات

نام: _____

بچے سے آپکا رشتہ: ماں [] باپ [] نانا [] نانی [] دادا [] دادی []

کوئی اور رشتہ _____

پتہ: _____

کتابچے کے مواد و ترتیب سے متعلق سوالات

سوال نمبر 1: اگر آٹزم کی تشخیص کے فوری بعد یہ کتابچہ بچے کے والدین کو دیا جائے تو آپ کے خیال میں کیا اس میں آٹزم کے حوالے سے بنیادی و مختصر معلومات کو صحیح انداز میں بیان کیا گیا ہے۔ (ہاں) / (نہیں)

سوال نمبر 2: کیا معلومات کی ترتیب درست ہے؟ (ہاں) / (نہیں)

سوال نمبر 3: کیا آپ نے اس کتابچے کو مفید پایا؟ (ہاں) / (نہیں)

سوال نمبر 4: اگر آپکو یہ کتابچہ مفید لگا تو کس انداز میں یہ کتابچہ آپ کے یا آپ کے بچے کے لیے مفید ثابت ہوا؟

_____

_____

سوال نمبر 5: اس کتابچے کو آپ نے مندرجہ ذیل حوالوں سے کیسا پایا؟

(i) کتابچے میں استعمال کی گئی زبان:

سمجھنے میں آسان [] قابل قبول [] سمجھنے میں مشکل []

(ii) کتابچے کا سائز (حجم):

بہت ہی چھوٹا [] مناسب و اچھا [] بہت ہی بڑا []

(iii) کتابچے کی لکھائی کا سائز:

بہت ہی چھوٹا [] مناسب و اچھا [] بہت ہی بڑا []

(iv) کتابچے میں دی گئی معلومات:

بہت ہی مختصر [] مناسب وقابل قبول [] بہت زیادہ طویل []

(v) کتابچے میں استعمال کیے گئے رنگوں کا امتزاج:

بہت ہی مدھم و پھیکا [] مناسب وقابل قبول [] بہت زیادہ رنگین []

(vi) مواد کی مطابقت:

متعلقہ [] مناسب وقابل قبول [] غیر متعلقہ []

(vii) مواد کی افادیت (یعنی اس میں فراہم کردہ معلومات کی اہمیت):

بہت ہی مفید [] قابل قبول [] غیر مفید یا بے کار []

(viii) موضوعات کی تفصیل ووضاحت:

عمدہ وبہترین تفصیل [] مناسب وقابل قبول تفصیل [] نامناسب تفصیل یا غیر واضح موضوعا []

سوال نمبر 6: اس کتابچے میں کونسے موضوعات آپ کو مفید وبہترین لگے؟

_____

_____

سوال نمبر 7: اس کتابچے میں کونسا موضوع آپ کو بے کار وفالتو لگا؟

_____

_____

سوال نمبر 8: کیا اس کتابچے میں کوئی تبدیلی کرنی چاہیے؟ اگر ہاں تو کس قسم کی تبدیلی کرنی چاہیے؟

_____

_____

سوال نمبر 9: کیا اس کتابچے میں مزید معلومات (مواد) شامل کرنی چاہیے؟ (ہاں) / (نہیں)

_____

_____

سوال نمبر 10: اگر آپ کے خیال میں مزید معلومات شامل کرنے سے یہ کتابچہ بہتر بنایا جا سکتا ہے تو کونسی معلومات اس میں شامل کی جائیں؟ تفصیل تحریر کریں۔

_____

_____

سوال نمبر 11: کیا اس کتابچے سے کچھ موضوعات (معلوماتی مواد) کو کم کرنا چاہیے (ہاں) / (نہیں)

_____

_____

سوال نمبر 12: اگر آپ کے نزدیک کچھ موضوعات کو کم کرنے سے یہ کتابچہ مفید ہو سکتا ہے تو کونسے موضوعات کو اس کتابچے سے نکال دیا جائے؟

_____

_____

سوال نمبر 13: کیا آپ کے خیال میں یہ کتابچہ خاندان کے دیگر افراد کے لیے یا بچے کے اساتذہ کے لیے بھی مفید ثابت ہو سکتا ہے؟ (ہاں) / (نہیں)

سوال نمبر 14: اگر آپ مزید کوئی رائے یا تجویز دینا چاہیں تو یہاں درج کریں۔

_____

_____

_____

_____

(آپ کے تعاون کا شکریہ)

APPENDIX N: Urdu version of the questionnaire used with professionals target group to evaluate the 'Parent Information and Guidance Booklet' – Consent Form, Questionnaire Information Sheet, and the Questionnaire.

University of Wales, Newport
Newport School of Education
Prifysgol Cymru, Casnewydd
Ysgol Addysg Casnewydd

ANOLFAN DYSCOVERY CENTRE

سروے کا موضوع : آٹزم میں مبتلاء بچو ں کے والدین کے لیے معلوماتی وتربیتی کتابچے کا جائزہ

اجازت نامہ

مجھے معلوم ہے کہ اس تحقیق میں میری شمولیت کا مقصد ایک سوالنامے کو پر کرنا ہے جسے پر کرنے میں تقریباً تین سے پانچ منٹ کا وقت لگے گا۔ یہ سوالنامہ ایک معلوماتی وتربیتی کتابچے کا جائزہ لینے کے لیے بنایا گیا ہے۔ جو آٹزم میں مبتلاء بچوں کے والدین کی تربیت کے لیے تیار کیا گیا ہے۔

مندرجہ ذیل سوالات کے جواب میں ہاں یا نہیں پر نشان لگائیں۔

1۔ مجھے معلوم ہے کہ اس تحقیق میں میری شمولیت رضا کارانہ ہے اور میں کسی بھی وقت بغیر وجہ بتائے اس میں شمولیت سے انکار کر سکتا/ سکتی ہوں۔ (ہاں) / (نہیں)

2۔ مجھے معلوم ہے کہ میں کسی بھی وقت تحقیق سے متعلق سوال پوچھ سکتا/ سکتی ہوں۔ (ہاں) / (نہیں)

3۔ مجھے معلوم ہے کہ میری طرف سے فراہم کی گئی معلومات کو صیغہ راز میں رکھا جائے گا۔ (ہاں) / (نہیں)

4۔ مجھے معلوم ہے کہ معلومات کے تحفظ کے قانون کے پیش نظر معلومات کو ہمیشہ برقرار رکھا جا سکتا ہے۔ (ہاں) / (نہیں)

5۔ مجھے معلوم ہے کہ میں اپنی فراہم کردہ معلومات کی منسوخی یا کسی بھی قسم کے خدشات پر محقق سے بات چیت کر سکتا/ سکتی ہوں۔ (ہاں) / (نہیں)

اگر آپ اس تحقیق میں حصہ لیے پر رضامند ہیں تو مندرجہ ذیل لائن پر اپنا نام درج کریں۔

میں اس تحقیق میں حصہ لینے پر رضامند ہوں۔

نام:_____

تحقیق سے متعلق مزید معلومات کے حصول کے لیے محقق سے فون یا ای میل پر رابطہ کیا جا سکتا ہے۔

فون نمبر: 00923216302500, 00447424548080

ای میل نمبر: maria_sohaib@hotmail.com, dyscoverycentre@southwales.ac.uk

(آپ کے تعاون کا شکریہ)

University of Wales, Newport
Newport School of Education

Prifysgol Cymru, Casnewydd
Ysgol Addysg Casnewydd

CANOLFAN DYSCOVERY CENTRE

سوالنامے کے بارے میں معلومات

مجوزہ سوالنامے کا مقصد:

اس سوالنامے کا مقصد ایک معلوماتی و تربیتی کتابچے کی افادیت کا جائزہ لینا ہے جو آٹزم میں مبتلاء بچوں کے والدین کے لیے تیار کیا گیا ہے۔

مجوزہ تحقیق کا بنیادی مقصد:

جیسا کہ مجوزہ تحقیق کے آغاز میں، آٹزم میں مبتلاء بچوں کے والدین کے لیے پاکستان میں کوئی معلوماتی و تربیتی مواد اردو میں موجود نہ تھا، جو والدین کی ضروریات کے پیش نظر بنایا گیا ہو۔ لہٰذہ مجوزہ تحقیق کا بنیادی مقصد آٹزم میں مبتلاء بچوں کے والدین کے لیے ایسے معلوماتی و تربیتی مواد تیار کرنا ہے، جو والدین کی ضروریات کے عین مطابق بھی ہوں، اور ماہرین کی رائے کے بھی، نیز دنیا بھر میں آٹزم کے لیے استعمال کیے جانے والے مواد کے معیار کے مطابق ہوں۔

مجوزہ تحقیق میں شمولیت کے لیے کن لوگوں کو مدعو کیا گیا ہے؟

پاکستان بھر میں آٹزم میں مبتلاء بچوں اور ان کے والدین کے لیے کام کرنے والے ماہرین (جیسا کہ ڈاکٹر، وغیرہ)

مجوزہ تحقیق میں شمولیت کی صورت میں کیا کرنا ہوگا؟

اگر آپ اس تحقیق میں شامل ہونے پر رضامند ہوں تو آپ کو ایک سوالنامہ پر کرنے کو دیا جائے گا، جسے پر کرنے میں تقریباً پانچ منٹ لگیں گے۔ سوالنامے کا مقصد آٹزم میں مبتلاء بچوں کے والدین کے لیے تیار کردہ معلوماتی و تربیتی کتابچے کے مواد و ترتیب کے بارے میں آپکی رائے و تجاویز لینا ہے۔ آپ کی رائے اس ضمن میں بہت اہم کردار ادا کر سکتی ہے۔

فراہم کردہ معلومات کا استعمال:

مجوزہ تحقیق یونیورسٹی آف ویلز نیوپورٹ کی اخلاقی کمیٹی سے منظور شدہ ہے۔ یہ تحقیق پروفیسر امنڈا کربی کی نگرانی میں کی جارہی ہے۔ آپ کی فراہم کردہ معلومات کو صیغہ راز میں رکھا جائے گا۔

اگر آپ کو کوئی بھی سوال پوچھنا ہو یا رائے دینی ہو تو ماریہ قریشی سے رابطہ کریں۔

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ای میل: maria_sohaib@hotmail.com / dyscoverycentre@southwales.ac.uk

(آپ کے تعاون کا شکریہ)

آٹیزم میں مبتلاء بچوں کے والدین کے لیے معلوماتی و تربیتی کتابچے کا جائزہ نامہ

بنیادی معلومات

نام: _____ پیشہ: _____

پتہ: _____

کتابچے کے مواد و ترتیب سے متعلق سوالات

سوال نمبر 1: اگر آٹیزم کی تشخیص کے فوری بعد یہ کتابچہ بچے کے والدین کو دیا جائے تو آپ کے خیال میں کیا اس میں آٹیزم کے حوالے سے بنیادی و مختصر معلومات کو صحیح انداز میں بیان کیا گیا ہے۔ (ہاں) / (نہیں)

سوال نمبر 2: آپکے خیال میں، کیا یہ کتابچہ آٹیزم میں مبتلا بچے کے والدین کے لیے موزوں ہے؟ (ہاں) / (نہیں)

سوال نمبر 3: کیا معلومات کی ترتیب درست ہے؟ (ہاں) / (نہیں)

سوال نمبر 4: اس کتابچے کو آپ نے مندرجہ ذیل حوالوں سے کیسا پایا؟

(i) کتابچے میں استعمال کی گئی زبان:

سمجھنے میں آسان [] قابل قبول [] سمجھنے میں مشکل []

(ii) کتابچے کا سائز (حجم):

بہت ہی چھوٹا [] مناسب و اچھا [] بہت ہی بڑا []

(iii) کتابچے کی لکھائی کا سائز:

بہت ہی چھوٹا [] مناسب و اچھا [] بہت ہی بڑا []

(iv) کتابچے میں دی گئی معلومات:

بہت ہی مختصر [] مناسب و قابل قبول [] بہت زیادہ طویل []

(v) کتابچے میں استعمال کیے گئے رنگوں کا امتزاج:

بہت ہی مدھم و پھیکا [] مناسب و قابل قبول [] بہت زیادہ رنگین []

(vi) مواد کی مطابقت:

متعلقہ [] مناسب و قابل قبول [] غیر متعلقہ []

(vii) مواد کی افادیت (یعنی اس میں فراہم کردہ معلومات کی اہمیت):

بہت ہی مفید [] قابل قبول [] غیر مفید یا بے کار []

(viii) موضوعات کی تفصیل و وضاحت:

عمدہ و بہترین تفصیل [] مناسب و قابل قبول تفصیل [] نامناسب تفصیل یا غیر واضح موضوعات []

سوال نمبر 5: اس کتابچے میں کونسے موضوعات آپ کو مفید و بہترین لگے؟

سوال نمبر 6: اس کتابچے میں کونسا موضوع آپ کو بے کار و فالتو لگا؟

سوال نمبر 7: کیا اس کتابچے میں کوئی تبدیلی کرنی چاہیے؟ اگر ہاں تو کس قسم کی تبدیلی کرنی چاہیے؟

سوال نمبر 8: کیا اس کتابچے میں مزید معلومات (مواد) شامل کرنی چاہیے؟ (ہاں) / (نہیں)

سوال نمبر 9: اگر آپ کے خیال میں مزید معلومات شامل کرنے سے یہ کتابچہ بہتر بنایا جا سکتا ہے تو کونسی معلومات اس میں شامل کی جائیں؟ تفصیل تحریر کریں۔

سوال نمبر 10: کیا اس کتابچے سے کچھ موضوعات (معلوماتی مواد) کو کم کرنا چاہیے؟ (ہاں) /(نہیں)

سوال نمبر 11: اگر آپ کے نزدیک کچھ موضوعات کو کم کرنے سے یہ کتابچہ مفید ہو سکتا ہے، تو کونسے موضوعات کو اس کتابچے سے نکال دیا جائے؟

سوال نمبر 12: کیا آپ کے خیال میں یہ کتابچہ بچے کے خاندان کے دیگر افراد کے لیے یا بچے کے اساتذہ کے لیے بھی مفید ثابت ہو سکتا ہے؟ (ہاں) / (نہیں)

سوال نمبر 13: اگر آپ مزید کوئی رائے یا تجویز دینا چاہیں تو یہاں درج کریں۔

(آپ کے تعاون کا شکریہ)

APPENDIX O: Letter to head teacher

University of Wales, Newport School of Education

Prifysgol Cymru, Casnewydd Ysgol Addysg

CANOLFAN DYSCOVERY CENTRE

Dear Sir/Madam,

I am currently pursuing my PhD in Autism at the University of Wales, Newport, UK. The research project that I'm undertaking is intended to explore the appropriate methods of providing information to parents of children with Autism Spectrum Disorder (ASD) living in Pakistan. As you may be aware, at the present time there are no specific need oriented 'Parent Information and Guidance Booklets' in Urdu for parents of children with ASD living in Pakistan. A booklet has been designed (as a part of the study) that incorporates an understanding of parents' needs, the professionals' consideration of appropriate content and the evidence base that supports the current understanding of ASD. The booklet is likely to be given to the parents soon after their child's diagnosis, and contains brief and useful information about autism.

The booklet is being piloted at the moment, and this survey is intended to find out the effectiveness of it. Thus, I would be grateful if you would allow me to use your teaching staff for my study. This will involve reading of the booklet, and completion of a brief questionnaire designed to evaluate the effectiveness of the booklet. The booklet and the questionnaire will be distributed by which ever means you deem most feasible.

I would like to add that this project is approved by the Ethics Committee of University of Wales, Newport, UK. Furthermore, all the information provided by you will be treated as confidential.

If you have any questions or comments please feel free to contact Maria Qureshi at maria_sohaib@hotmail.com, dyscoverycentre@southwales.ac.uk or 00447424548080, 00923216302500.

I truly appreciate your help in this project, which will benefit not only me in my studies, but also many children affected by autism and their families living in Pakistan.

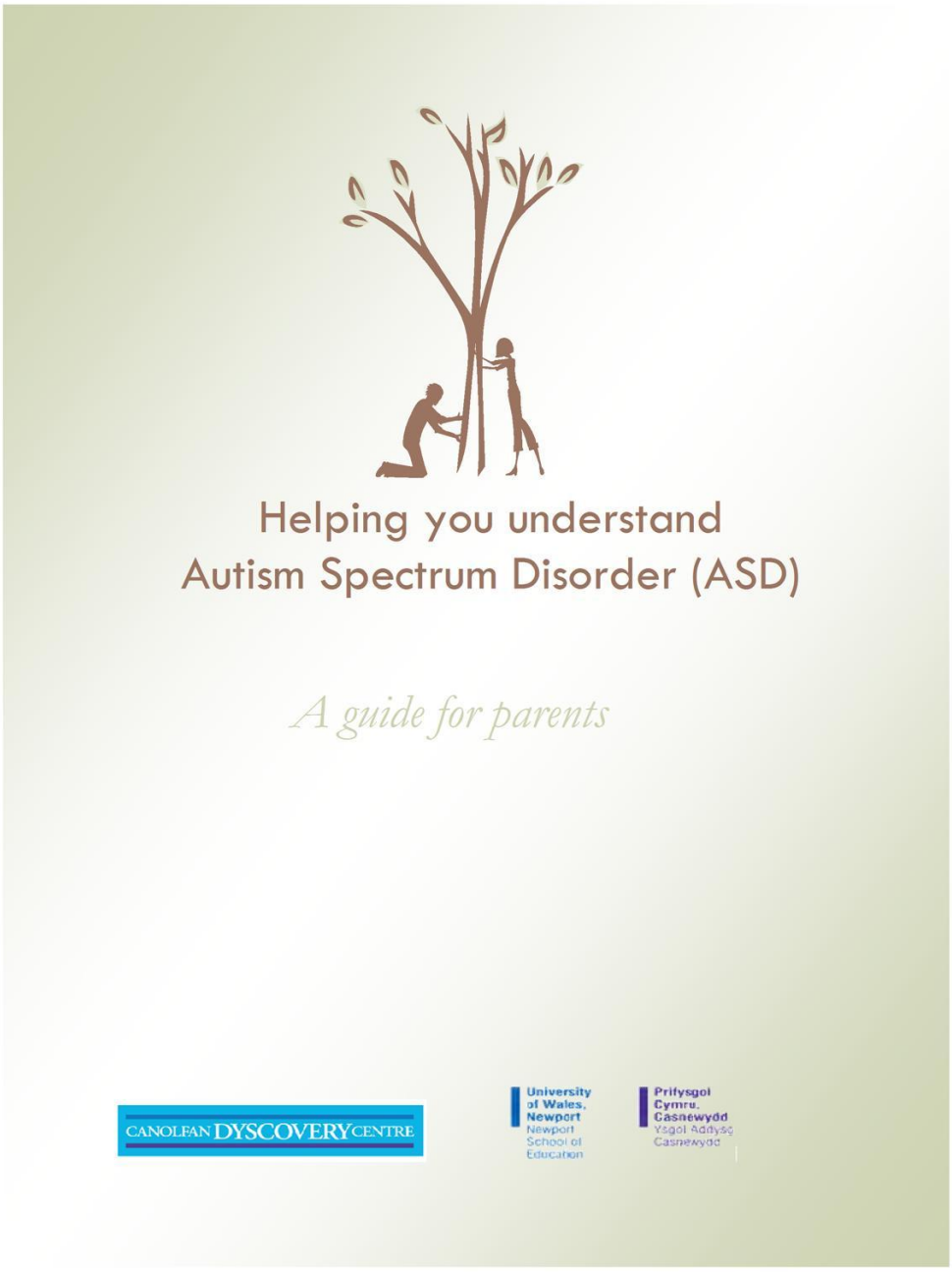
I thank you in advance

Yours sincerely
Maria Qureshi

The Dyscovery Centre
Felthorpe House
University of South Wales
Caerleon Campus, Lodge Road,
Caerleon
NP18 3QR
U.K.

Thank you in advance for your time and help.

APPENDIX P: 'Parent Information and Guidance Booklet' designed for Parents of children with Autism Spectrum Disorder (ASD) living in Pakistan



BOOKLET BRIEF

This booklet is written primarily for parents and carers of a child that has been diagnosed with an autism spectrum disorder. It can also be of interest to other family members, and professionals who work with the child such as paediatricians, therapists, teachers, etc.

This booklet aims to:

- Provide a basic understanding of autism spectrum disorders
- Give information on some of the most commonly asked questions about autism
- Explain possible difficulties individuals on the spectrum may have and offer strategies to help.

This booklet is written by Maria Qureshi
with the help of Professor Amanda Kirby

What is Autism?

Autism is a complex developmental disorder that typically appears within the first three years of life. It is part of a group of disorders known as Autism Spectrum Disorder (ASD). It is usually present from birth (though not always obvious) and lasts throughout a persons' life.

Autism is known as a spectrum disorder because it affects each individual differently and to varying degrees. Symptoms can range from very mild to quite severe. Autism impairs a person's ability to communicate and relate to others. It is also associated with rigid routines and repetitive behaviours, such as obsessively arranging objects, or following very specific routines.

Children and adults with autism typically display major impairments in three areas which are referred to as the 'Triad of Impairments'.

The three areas of difficulty which all people with autism share are:

- Difficulty with social communication
- Difficulty with social interaction
- Difficulty with imagination

Many people with autism also have sensory difficulties e.g. over or under sensitivity to sight, touch, taste, smell, sound, or pain. Because of their impairments, people with autism often experience overwhelming anxiety, frustration, and confusion when faced with the demands of everyday life.

How many people have autism?

People from any country, culture, religion and social background can have autism. Around 1 in 100 people are likely to have autism and it is four times more likely to affect boys than girls.

What is the cause of autism?

The real cause of autism is still unknown. Researchers are trying to investigate the exact cause of it. However, there does appear to be a mixture of environmental and genetic factors at play. Research suggests that a combination of these factors may result in the changes in the brain development.

Few important facts to be noted:

- Autism is not caused by bad parenting (i.e. a person's upbringing, inadequate parenting skills, the amount of love/care parents give to the child, their social circumstances etc).

- Autism is not caused by lack of love.
- Mothers don't have any role to play in causing autism.
- Women should not be blamed for giving birth to a child with autism.
- Having one child with autism does not mean that all other children will be born with this disability.
- Autism is not an illness that other children, siblings or adults may catch.

Are there any cures for autism?

There is no cure for autism at the moment/to date. However, development and changes occur and progress is possible. For many years, researchers have been trying to find a cure for autism, but as yet nothing has been found to reverse all the effects of the disability. Although it is a lifelong disorder with no cure, there are a wide range of treatments and intervention approaches that can help reduce some of the difficulties and help to manage behaviour problems.

Why should I give a label of autism to my child?

It is hard for parents to accept that their child has autism, but avoiding a diagnosis through the fear of labelling can cause plenty of problems for the child. If autism is identified at an early age, treatment can be started immediately. Research indicates that starting intervention/treatment at an early age can result in great progress and improvement in the child.

Is it important to identify autism? If so, why?

Yes, it is important to identify or diagnose autism. Having a diagnosis can be helpful for the following reasons:

- It may increase our understanding of people with autism.
- It may assist in choosing appropriate interventions for people with autism which may help to reduce autism-like features.
- Some children with autism may have intolerance to certain food items. Getting a diagnosis may help to raise awareness of those food sensitivities. Avoiding those food items may help to reduce hyperactivity, digestion problems, anxiety, and some other conditions in the child.
- Some children with autism have sensory problems. They may harm them, flap their hands, bite their wrists, spin around, or may be sensitive to light, sound and touch etc. These issues can be resolved by timely diagnosis and early intervention.

- Some children may not talk or may have very limited speech. Others may find it difficult to interact with others. All these problems of socialization and communication can be addressed by getting a diagnosis and starting appropriate treatment.
- Diagnosis may also help in choosing the right school for the child.
- It may allow people to access support services.

What are the key features (symptoms) of autism?

The key features of autism vary from individual to individual. However, some major group of difficulties which people with autism typically display are discussed below.

1. **Difficulty with social communication**

   Children and adults with autism show a range of difficulties in social communication that include both verbal and non-verbal communication. Some people on the spectrum may not develop speech (or may not speak), while some others may have fairly limited speech, or may not have functional speech. The development of language is often delayed and may follow a different pattern from that of typically-developing children.

   They find it hard to:
   - Communicate clearly what they want or need
   - Use gestures and facial expressions in communication
   - Understand gestures and facial expressions of others (e.g. they may find it hard to understand by looking at others' faces that they are happy, sad or upset)
   - Use tone of voice according to the situation
   - Understand tone of voice of others
   - Use or understand jokes
   - Imitate actions or sounds
   - Understand word meanings
   - Use or understand common phrases
   - Express their feelings
   - Initiate communication/start a conversation
   - Carry the conversation on with 'give and take' between the two people

   Some people with autism may use unusual vocal intonation/rhythm (or may have unusual or odd speech), while others who have good language skills may talk at length about their own interests. Repeating language, either in words or phrases, from videos or elsewhere over and over again (known as echolalia) is also found in some children with autism.

IDEAS THAT MAY HELP:

- **Use simple language:** Use simple or easy-to-understand language.
- **Avoid idioms:** Try to avoid the use of idioms and phrases.
- **Avoid words with two meanings:** Do not use words that may have more than one meaning.
- **Use clear words or concrete terms:** Try to avoid the use of ambiguous words or abstract terms, for example, instead of saying, 'We shall go to the park later', try saying, 'We shall go to the park after dinner' or 'We shall go to the park at 7 p.m.'.
- **Reduced language:** Do not use long sentences. Try to use the smallest sentences possible.
- **Get the child's attention:** Try to get the child's attention before starting the conversation; when you speak to the child, first get his attention.
- **Use the child's name:** Try to use the child's name when you speak to him to get his attention, and to make it clear who you are talking to.
- **Give additional time to respond:** Try to wait for the child to respond. The child may take more time to process information than typically-developing children; give the child some extra time to process the information.
- **Give clear instructions:** Try to give clear instructions to the child, for example, instead of saying, 'All children should get into bed', try saying, 'Sara, get into bed'.
- **Give instructions in order:** The child may have problems in rearranging the instructions and putting them in order. Therefore, try to give instructions in the order in which they should happen. For example, instead of saying, 'Get into the car after putting your shoes on when you have finished taking your lunch, as we are going to the park', try saying, 'Finish your meal first. Then put your shoes on. Then get into the car. We are going to the park'.
- **Give one instructions at a time:** Try to avoid giving several instructions at a time (as shown in the above example). Try to give one or two instructions to the child at a time. When he finishes doing that, then give more instructions.
- **Give positive instructions:** Give positive instructions to the child. Instead of telling them what they should not do, tell them what they should do. For example, instead of saying, 'Do not throw rubbish around', try saying, 'Ahmad, throw the rubbish in the bin'.
- **Introduce the concept of "First" and "Then":** For example, if you want the child to perform a certain activity, you can say, 'First eat, then video game'.

- **Give choices:** For example, if it is play time for the child, you can ask the child to choose one object/activity from his favourites (e.g. choose one from: cars, computer, video game or park). Choices can be used at lunch time or for any other thing, for example, the child can be asked to choose one food from banana, chips, biscuits or sandwiches.
- **Introduce the concept of "Finish":** For example, when one activity or task finishes, show a "Finish" card to the child or simply say, "Finished".
- **Use visual aids to clarify the message**

2. Difficulty with social interaction

People with autism experience some degree of difficulty in social interaction. Some of them may not seek out contact with others and seems to be happy in their own company. Others may want to interact with other people and make friends, but may find it hard to do so.

They often have difficulty in:

- Understanding other people's feelings and emotions
- Expressing their feelings and emotions
- Sharing excitement and pleasure with others
- Playing with others (the child with ASD may avoid peers, preferring to be with adults or children of a different age; the child may also prefer games he can play alone, like cars, toys, etc).
- Forming friendships
- Sharing (the child may grab toys or food from other children, and may not share his toys with others)
- Turn-taking
- Understanding the perspective of others
- Understanding social rules (e.g. how to behave in a particular situation)
- Approaching others (e.g. standing too close to another person, repetitively questioning or pushing another person to get attention, etc.).

Their limited social understanding can lead to behaviour that appears inappropriate to others. For example, people may consider them insensitive if they don't show sympathy on someone's pain, distress or discomfort. But they may show no reaction on someone's pain as they may find it hard to recognise feelings of others and also find it hard to express their feelings.

IDEAS THAT MAY HELP:

- **Joint attention:** Introduce games to the child in which he/she has to interact with another person, for example, blowing the bubbles.
- **Playing by the child's side:** If the child with autism doesn't allow anyone to join in his play, sit near the child where he can see you, and copy his play. This may help him to tolerate other people around him sharing his play.
- **Joining in the child's play:** Whatever the child likes to play (such as with cars or another toy, or with water etc.), join him in it. If he does not like to play with his brothers or sisters, then parents should join him initially. Later on when the child gets used to his parents' presence, brothers and sisters can also be introduced/included into the play.
- **Turn taking:** Help the child to learn the concept of turn taking. For example, during play, meal time or during any other activity, you can say to the child on his turn, 'Ahmad's turn', and then on your turn, 'mama's turn'.
- **Accept the child's privacy:** A child with autism may find it hard to interact with people, and may need time to be on his own. This may help him calm down. So after the hectic activity of socializing, give him some time to be alone.
- **Express your feelings in words:** Try to express your feelings and emotions in words in addition to gestures. The child may have difficulty reading your emotions, so explain him. It will help the child to understand that others have feelings too. It will also help to explain the most appropriate way of expressing emotions. For example, if you are happy with an action of the child, tell him with a smile, that you are happy with this action.
- **Help the child to express his feelings:** For example, if you give the child's favourite toy or food to him, tell him that he is happy on having his favourite toy. You can use child's name in the sentence to make it clear to the child that you are talking about child and his emotions, for example, if the child's name is Ahmad, say, 'Ahmad is happy on having this toy'.
- **Explain social rules:** Explain the rules of a social situation, for example, how to behave in front of a guest, or in a super store, or in the mosque, etc. The child may find it hard to learn just by observation.
- **Help the child to get used to social gatherings:** Don't keep the child at home due to his tendency to cry a lot in a gathering. Try to take him out with you to the market, to weddings, birthday parties, etc. If the child cannot tolerate the situation at all, first start with 5 minutes, then increase the time gradually. After sitting in a gathering for 5 minutes, one parent can leave the gathering with the child. Gradually the child may develop the stamina/resistance for a social gathering.

3. **Difficulty with imagination**

Children and adults with autism show a range of difficulties with imagination. Some may not be able to make sense of the world around them, predict the behaviour of other people or guess what other people are thinking; while others may focus on the details of an object rather than the bigger picture (e.g. looking at the wheels of a car, rather than playing with the whole car).

People with autism find it difficult to:

- Engage in imaginative play and activities (e.g. typically-developing children sometimes act like a doctor or a teacher during pretend play, or may consider their doll a child and feed it with spoon or bottle etc. But children with ASD may lack all these things)
- Make sense of danger/ understand the concept of danger (e.g. a child may hit someone with a sharp or heavy thing without being aware of it that it may hurt him, or a child may pull a pan of boiling water without thinking that it may burn him, or may run into the middle of a busy road without foreseeing the danger of an accident)
- Understand or predict the behaviour of other people
- Predict an upcoming situation or what may happen next
- Prepare for change
- Cope with new or unfamiliar situations
- Plan for the future

Despite difficulties in the area of imagination in relation to social situation, some people with autism may be extremely creative and imaginative. For example, an individual with autism with a special interest in music, art or writing, may become a great artist, musician or writer.

IDEAS THAT MAY HELP:

- Establish a daily and weekly schedule
- Inform him about upcoming changes
- Introduce change gradually
- Use visual aids or timetables to introduce change
- Help the child to improve his imaginative thinking: Let him think about more than one situation or discover more than one solution. Describe how something can be used in more than one way, for example, a bed can be used for sleeping, and to sit on, etc. A garden can be used for play, for parties, for a walk, etc.

- Try to involve the child in imaginative play. For example, if a child is playing with a doll, you can arrange a wedding for the doll, or if child plays with cars, you can create a racing competition.

Additional/associated features (symptoms):

4. Sensory difficulties

Children and adults with autism may show a range of sensory difficulties as well. They may show some degree of difficulty in sound, vision, touch, taste, smell, or balance and body awareness. The child may be hyper-sensitive (may over-react to sensory stimuli) or hypo-sensitive (may under-react to sensory stimuli).

The possible difficulties an individual with autism may have include:

❖ Balance and body awareness:
- May rock, spin around, flap their hands
- May stand too close to others
- May bump into people
- May have difficulties navigating rooms
- May have difficulties avoiding obstructions
- May have difficulties with fine motor skills/tasks (e.g. doing up buttons, tying shoe laces etc.)

❖ Sound:
- May exhibit panic to specific sounds
- May sometimes seems deaf
- May dislike loud noises, crowded places
- May dislike sudden, unexpected sounds (such as a dog barking etc.)
- May dislike high-pitched or continuous noises
- Some may like noisy places, and may bang doors and objects
- May have difficulty filtering out unwanted sounds

❖ Vision/sight:
- May play with light and reflections
- May have problems with throwing and catching
- May flick fingers before eyes
- May have sensitivity to light or a particular level of illumination
- May have difficulty filtering out unwanted movements or sights in a visually-busy environment

❖ Touch:
- May not like to be touched
- May have difficulty in brushing and washing hair, cutting nails, wearing clothes

- May only like certain types of clothing
- May not like anything on hands or feet
- May hold others tightly
- May not feel pain
- May not feel extremes of temperature
- May harm himself
- May enjoy heavy objects on top of him

❖ Taste:

- may like very spicy food
- may eat everything (e.g. soil, grass, materials)
- may only like certain types of foods and flavours

❖ Smell:

- may have no sense of smell and fail to notice extreme odours
- may lick strong-smelling objects
- may have toileting problems
- may dislike perfumes and shampoos etc.

It is not necessary for all children with autism to have all the difficulties described above. Some children may experience some of these, while others may not have any of these at all.

IDEAS THAT MAY HELP:

❖ **Sensory-friendly environment:** Try to develop a comfortable environment according to the child's needs that may reduce the risk of possible anxiety due to sensory overload.

❖ **Inform him about change in advance:** Tell the child in advance about any possible sensory change or overload. For example, if you are taking the child to a supermarket, tell him in advance that you are going into a supermarket and it can be noisy, etc.

❖ Ideas related to balance and body awareness system:

- Try to encourage the child to participate in activities such as playing on swings, sea-saws or rocking horses etc., to help develop the balance and body-awareness system.
- Try to encourage the child to take part in threading, drawing, painting activities and puzzles to stimulate fine motor development.

- Try to organise the room furniture in a way that makes it easy to walk. Too much furniture all around can make it hard for the child to navigate easily.
- To help the child with the concept of personal space, try using different strategies, such as the arm's length rule, (the children who stand too close to a person, being unaware of personal space, for them make a rule that whenever they go to talk to a person, they should first hold out their arm to check if they are at an appropriate distance from the other person.)

- Ideas to help difficulties related to sound:
  - Prepare the child in advance if you are taking him to a noisy place
  - If the child is sensitive to sound, arrange a less noisy area in the house away from the main sitting area and kitchen (perhaps a bedroom or a corner in a room) where the child can spend some time to relax and to calm down.
  - Personal stereos can be a good choice to cut down unwanted external noises.
  - Ear plugs can also be used.
- Ideas related to difficulties with vision/sight:
  - If the child is sensitive to bright lights, use dimmed lights or deep-coloured bulbs.
  - Use dark curtains.
  - Sunglasses can be used when going out.
- Ideas related to difficulties with touch:
  - For children who don't like to be touched, tell them before you are about to touch or hug them.
  - Allow the child to wear clothes he is comfortable in.
  - Gradually introduce different textures.
  - Children, who like heavy objects on top of them, a quilt or weighted blanket could be a good option.
  - Use water or soft play.
- Ideas related to difficulties with taste:
  - Gradually introduce different type of foods.
  - Change the texture of the food, e.g. mash it etc.
  - Try to encourage the child to participate in activities which involve mouth such as blowing, chewing etc.
- Ideas related to difficulties with smell:
  - Some children who have a weak or no sense of smell may lick some strong-smelling things or may like to smell faeces etc. To avoid such problems, pleasant-smelling products can be used to distract children from inappropriate objects. These can also be used as rewards for child's good behaviour.
  - Children who are over-sensitive to smell may find it hard to cope with the strong smell of perfumes, shampoos etc. For these people fragrance-free products can be a good choice.

Some important considerations:

All the ideas given above should not be tried on every child, as each child's difficulty is different. Therefore, the ideas related to your child's particular difficulty are likely to help.

Another important thing to be noted is that the child should be helped in managing sensory difficulties. Although the child should be provided with a comfortable environment which considers his sensory difficulties to reduce the risk of possible anxiety, complete avoidance can make the child even more sensitive. Gradual exposure is essential to reduce the sensitivity of the child.

5. Resistance to change and love of routines

Children and adults with autism may find it difficult to make sense of the world. The world may appear to them a very confusing and unpredictable place.

To overcome possible anxiety and fear of a rapidly-changing environment, they may:

- Prefer order and routines.
- Want to travel the same way to school, park or a takeaway etc.
- Dislike change (e.g. changing house or school, moving or changing objects, furniture, toys or any other thing).
- Prefer to eat exactly the same food or wear the same clothes, etc.

IDEAS THAT MAY HELP:

- Introduce change gradually
- Warn the child in advance about any change
- Give reasons for that change
- Use the child's love of routine to help in organizing the child's daily activities and his behaviour.
- Use timetables to organise the child's day

6. Special Interests

Many children and adults with autism may have special interests of an intense nature. They are likely to become very upset if they are asked to stop doing their favourite activity in order to do something else.

They may:

- Have an intense interest in cars, trains, computers, a toy, a TV programme, an animal etc.
- Talk at great length (e.g. hours) about their favourite topic or interest.
- Not realise that others are tired of listening or do not share the same degree of interest
- Show great distress if their favourite toy/object has been taken from them

IDEAS THAT MAY HELP:

- Remember that the child may need some time to do his favourite activities.
- The child's special interest can be used as a reward for desirable behaviour. For example, if you want the child to perform a certain activity such as brushing the teeth, you can say, "first brush your teeth, then you'll get your cars".

DEALING WITH INAPPROPRIATE OR BAD BEHAVIOUR

Some children with autism may also have behaviour problems. Some commonly-asked questions about problematic/socially inappropriate behaviour are:

Q.1. Is it appropriate to stop a child with autism from behaving inappropriately?

Yes, it is very essential. Stopping children's bad behaviour or habits does not mean that you are suppressing the child. Just because a child has ASD, he/she should not be allowed to hit other children, run naked through the house, jump on guests, spit all over the house, throw objects and food all over the house, etc. Letting the child do whatever he wants, can result in the formation of socially-unacceptable habitual behaviours.

Q.2. Is it appropriate to beat a child with autism for inappropriate behaviour?

Beating a child does not solve the underlying problem/root cause of that undesirable behaviour. The child may repeat the same bad behaviour at some other time, or may start showing other inappropriate and more challenging behaviours. Therefore, beating should be avoided at all costs.

Research indicates that there is always some reason behind an action. If a child with ASD is showing an undesirable behaviour, it may be because he may have

difficulty communicating his needs, may have little understanding of what is expected from him, or may get anxious from sitting with guests or participating in a gathering, etc. Children with autism have problems understanding the world around them; therefore, inappropriate behaviour can be a result of misunderstanding.

An effective way of reducing inappropriate behaviour is to find the root cause of that behaviour and to address that cause.

Q.3. What are the possible triggers (reasons) for inappropriate behaviour?

- **Anxiety:** One possible reason for the child's misbehaviour can be anxiety. If the child gets stressed or tense due to any reason (such as an unpredictable or uncomfortable environment, inappropriate communication etc.), it can affect his behaviour.
- **Change:** Another reason for a child's bad behaviour can be change. It may include change of furniture, room, house, school, class, teacher, etc. It may also include transition from one task to another, one activity to another, vacation to term-time, etc.
- **Misinterpretation of others' behaviour:** As children with autism have difficulty understanding others' emotions and behaviours, they may misunderstand some behaviours and may consider it against their interests.
- **Inability to understand what is required from them:** Children with autism may have poor imagination and observation skills. They may not understand social rules and may find it hard to learn from observing others. They may not know how to behave with guests, how to behave in a super store or may not understand what parents want from them.
- **Inability to communicate their needs properly:** Children with autism may not know how to ask for a toy or biscuit, for example, they may snatch or grab it from others. Likewise, they may not be able to tell their parents that they want to go to a park and may start crying or throwing things, or hitting others.
- **Fear about what is going to happen:** Unpredictable environments can also cause anxiety or fear in children with autism and can be a reason for bad behaviour.
- **Uncomfortable environment:** As children with autism may have difficulties related to senses, socialization, communication and imagination, they may feel uncomfortable in certain environments. Social gatherings, noisy crowded places and sensory overloads such as bright lights, loud noises, strong smells, etc. can be examples of uncomfortable environments.
- **Inability to perform a longer task, or focus on the whole of a task.**

Q.4. What are possible strategies to control the inappropriate behaviour?

- **Be patient:** It may take time to change an inappropriate or bad behaviour. Don't lose hope if the child doesn't show improvements straight-away.
- **Be consistent:** Whatever strategy you use to control a child's bad behaviour, continue using it for some time. Don't change strategies every day. (Strategies don't work like a magic wand. It takes time to change a habit.)
- **Change your communication:** Good communication with children can solve many problems. (See the suggestions discussed above, under the heading of communication difficulties).
- **Analyse behaviour:** If the child shows any bad behaviour (such as hitting others, throwing things, crying, etc.), try to observe him. Notice things like when does he get upset and why. What is the reason behind the bad behaviour? Find the reason, and try to remove the problem or address the cause of the bad behaviour.
- **Prepare for change:** Tell the child in advance that you are going to change the furniture, home, school, class etc. (social stories, structures or time tables can be useful for it).
- **Ensure an autism-friendly environment:** Bright lights, loud noises, strong smells and many other things can cause anxiety in children with autism which may result in bad behaviour. The environment around them should be free from such triggers and should be comfortable for them.
- **Use structures:** Structures help children with autism understand what is expected from them and also inform them about what is going to happen.
- **Divide a longer task into small steps:** For example, teaching the child to wear trousers independently can be divided into three small steps: put legs into the trousers, button the trousers, and fasten the zip. Let the child learn each small task one by one.
- **Motivation:** Children may find it hard to learn anything or change their habits. Encourage them if they do something good and show appreciation for their efforts. Make them feel that they can do it.
- **Rewards:** The child should be given a reward for good behaviour or desirable activity. In the beginning, the child may not understand social praise, such as "Good work", etc, and may not consider it a reward. Initially, a child's favourite toy or activity can be used as reward. While giving the reward, add social praise as well to make the child familiar with it, for example, "Good boy", "Good work", "Well done", etc.

IDEAS TO HELP BROTHERS AND SISTERS OF ASD CHILD TO ACCEPT THE CHILD IN THE FAMILY

A child with ASD needs more time and care compared to typically-developing children. Parents' extra attention may cause anxiety or anger in brothers and sisters towards a child with ASD and they may feel ignored at times.

This issue can be resolved if:

- Parents have a balanced and positive approach to all children.
- Parents involve brothers and sisters of the child in taking care of the ASD child.
- Parents help the brothers and sisters of the child to feel that they are important and their role as carer of their ASD brother/sister is significant.
- Brothers and sisters of the child are given proper appreciation for helping their brother/sister with ASD.

Brothers and sisters of the child can help the child with ASD in many ways including socialisation, self help skills, interaction etc. They can work as a role model for the child and he may learn plenty of skills from them, such as turn taking, playing games, tolerating people around him, making friends, social interaction, self help skills, etc.

BRIEF INTRODUCTION OF TREATMENT AND INTERVENTION APPROACHES

There are plenty of treatments and intervention approaches that help in reducing a number of problems associated with ASD. Each individual with ASD shows unique patterns of behaviour; therefore it is hard to suggest only one therapy or treatment that may benefit all individuals. Certain people may find one therapy or treatment useful, while others may not. It is important to select the approach that meets the needs of the individual with ASD. For the purpose of information, a brief introduction of some of the treatments and therapies is included in this section.

Dietary intervention

Some children with autism may have intolerance to certain types of foods. Certain foods may have an effect on their behaviour, mood, learning and digestive system. Gluten and Casein are thought to have these effects. Gluten is a protein that is found in wheat and other grains such as oats, barley etc. Casein is a protein that is found in milk and the products of milk such as yogurt, butter, cheese etc. For some people with autism a gluten-free, casein-free diet may prove useful, but for others it may not be beneficial.

Biomedical intervention

There is no medicine that cures autism. However, some drugs may be used to treat some related conditions such as hyperactivity, anxiety etc. Some vitamins, minerals or food supplements are also used as a part of intervention.

Anti-depressants, anti-psychotic drugs or stimulant drugs may have some benefits, but with a potential to harm as well. Dosage and side effects of the drugs should be discussed with the practitioner if the child is put on medication.

Treatment and Education of Autistic and Communication Handicapped Children (TEACCH)

TEACCH is an effective intervention approach that is used worldwide. It focuses on moulding the environment according to the needs of individuals with autism. According to this approach, children with autism may have different styles of learning. They may not learn in the same way as typically-developing children. Therefore, if they are provided with appropriate conditions to learn in their own way, they may learn more effectively without becoming stressed.

In TEACCH, schedules are used to tell the child what is going to happen and in which order. The area where the child has to study or learn, may also be segmented into parts to minimise the distractions and also to specify which area is for which purpose. Work system is also a part of structured teaching. On the whole, this approach focuses on making the environment more predictable and organised for children with autism.

Applied Behavioural Analysis (ABA)

ABA is based on the theory that behaviours can be learnt if aided with appropriate reinforcement. The consequences of an action can either make behaviour weak or strong. If the result of an action is rewarding, then that will increase the frequency of that behaviour/ action, and the behaviour is repeated; this may lead to habit formation. Likewise, if the consequences of an action are negative, that would reduce the repetition of the particular action which may result in breaking a habit. Therefore the approach focuses on reinforcing the desired behaviours and ignoring, re-directing or discouraging inappropriate behaviours.

Augmentative and Alternative communication (AAC)

Children with autism may find it hard to interact with others, to communicate their needs or to use language for this purpose. AAC are methods that enhance communication or replace conventional ways of communication. Picture communication, choice boards and visual structures are examples of it.

Picture Exchange Communication System (PECS)

PECS is a communication system that provides an alternative to language and also helps children with ASD to start the communication process.

In PECS, the child gives the picture of the food item or toy or anything he wants to an adult. The adult, in response to the child's request, gives the requested food item or toy to the child. This is likely to help them understand that instead of grabbing things, there are other ways which are more acceptable. This way they may learn how to communicate for their needs, and also the importance of communication.

Social Stories

Children with autism may find it hard to learn from experience or to understand social rules automatically. To help them fit into social settings, social stories are used. These contain information about a social situation in a very easy format that children with autism can understand. Social stories can be developed for any social setting, for example 'going to the supermarket', 'attending Eid Prayer', 'attending school assembly', etc.

Speech and Language Therapy

Almost all children with autism have problems related to speech. Some are non-verbal or have fairly limited speech, while others who speak well may have a literal understanding of language. Speech and language therapy addresses issues related to language.

Occupational Therapy

Occupational therapists help children with autism with their daily living skills, social skills, play skill etc. They focus on the individual needs or deficits of the child and work with them to develop essential skills.

Sensory Integration Therapy

Sensory Integration Therapy involves gentle exposure to sensory stimuli to help the child overcome sensory difficulties. It includes a variety of materials or activities that may help in developing, strengthening and balancing the sensory system of the child. Disco lights, bubble tubes, mirror balls, soothing music, vibrating cushions, squeezing balls, water and soft play resources can be examples of materials used. It may involve exposure to particular sensory stimuli according to the child's needs. For example, for children who are sensitive to touch, handling materials of different textures can be included.

THE DYSCOVERY CENTRE

This booklet is published by The Dyscovery Centre which is an interdisciplinary centre of excellence for children and adults with specific learning difficulties.

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APPENDIX Q: Urdu version of the 'Parent Information and Guidance Booklet' designed for Parents of children with Autism Spectrum Disorder (ASD) living in Pakistan

1

کتابچے کا تعارف:

یہ کتابچہ آٹیزم میں مبتلا بچوں کے والدین کے لیے تیار کیا گیا ہے۔ تاہم خاندان کے دیگر افراد اور مختلف ماہرین (مثلاً بچے کے اساتذہ، ڈاکٹر، تھیراپسٹ وغیرہ) بھی اس سے مستفید ہو سکتے ہیں۔

اس کتابچے کا بنیادی مقصد یہ ہے کہ:

1- آٹیزم سپکٹرم ڈس آرڈر کے بارے میں مختصر اور بنیادی معلومات فراہم کرے۔

2- آٹیزم کے متعلق پوچھے جانے والے چند بنیادی سوالات کے جوابات فراہم کرے۔

3- آٹیزم میں مبتلا افراد کو پیش آنے والی مشکلات واضح کرے، نیز ان مشکلات پر قابو پانے کیلئے تجاویز فراہم کرے۔

یہ کتابچہ ماریہ قریشی نے پروفیسر امنڈا کربی کی مدد سے تحریر کیا ہے۔

2

آٹیزم (Autism) کیا ہے؟

آٹیزم ایک پیچیدہ مرض ہے، جو عام طور پر پیدائش ہی سے بچوں میں موجود ہوتا ہے اور تین سال کی عمر تک ظاہر ہو جاتا ہے۔ پھر تمام عمر انسان کے ساتھ رہتا ہے۔

یہ بیماریوں کے گروہ کا ایک حصہ ہے جسے آٹیزم سپکٹرم ڈس آرڈر (Autism Spectrum Disorder) کہا جاتا ہے۔ آٹیزم ہر شخص پر مختلف طریقوں سے اور مختلف سطح پر اثر انداز ہوتا ہے۔ کچھ لوگوں میں آٹیزم کی بہت سی علامات انتہائی شدت پر پائی جاتی ہیں۔ جبکہ بعض افراد میں بہت کم علامات اور انتہائی کم شدت پر پائی جاتی ہیں۔ یعنی تمام لوگوں میں آٹیزم کی علامات مختلف ہو سکتی ہیں۔ تاہم تین بنیادی مسائل ایسے ہیں، جو آٹیزم میں مبتلا تمام لوگوں میں کسی نہ کسی حد تک پائے جاتے ہیں یہ مسائل مندرجہ ذیل ہیں۔

1- گفتگو اور بات چیت میں مشکل محسوس کرنا۔

2- لوگوں سے ملنے جلنے اور تعلق رکھنے میں مشکل محسوس کرنا۔

3- خیالات اور سوچنے سمجھنے سے متعلق مسائل کا سامنا۔

آٹیزم میں مبتلا بہت سے افراد کو حسی مشکلات بھی درپیش ہوتی ہیں۔ مثال کے طور پر دیکھنے، سونگھنے، سننے، چکھنے، چھونے کی صلاحیتوں میں کمی یا زیادتی۔ ان مسائل کی وجہ سے آٹیزم میں مبتلا افراد روزمرہ زندگی کے معمولی کاموں کو سرانجام دیتے ہوئے بھی اکثر بے چینی، الجھن یا مایوسی کا شکار ہو جاتے ہیں۔

کتنے افراد آٹیزم میں مبتلا ہیں؟

آٹیزم کسی بھی ملک، ثقافت، مذہب اور سماجی طبقے کے لوگوں کو لاحق ہو سکتا ہے۔ تقریباً ہر سو میں سے

3

ایک فرد کو آٹیزم ہونے کا امکان ہے۔ اور یہ مرض لڑکیوں کی نسبت لڑکوں میں چار گنا زیادہ پایا جاتا ہے

کن وجوہات کی بناء پر آٹیزم ہوتا ہے؟

آٹیزم کی اصل وجہ ابھی تک معلوم نہیں ہوئی۔ دنیا بھر کے ماہرین اسکی اصل وجہ معلوم کرنے کی کوشش کر رہے ہیں۔ ماہرین نے بہت سے عوامل پر تحقیقات کی ہیں، مثلاً مختلف طرح کی ویکسین (MMR Vaccine وغیرہ)، دماغ کے حصے، جنسیاتی عوامل، ماحولیاتی عوامل وغیرہ۔ اب تک کی تحقیقات سے یہ ثابت ہوا ہے کہ جنسیاتی عوامل (Genetic factors) اور ماحولیاتی عوامل آٹیزم پیدا کرنے کا سبب ہو سکتے ہیں۔ یہ عوامل دماغ کی نشوونما کو متاثر کرتے ہیں اور دماغ کی درست نشوونما نہ ہونے کی وجہ سے بچے کو آٹیزم لاحق ہو جاتا ہے۔

آٹیزم سے متعلق چند اہم حقائق:

(i) آٹیزم بچوں کی غلط تربیت کی وجہ سے پیدا نہیں ہوتا۔

(ii) غربت، والدین کی ناتجربہ کاری، والدین کی طرف سے محبت اور دیکھ بھال میں کمی وغیرہ آٹیزم کے مرض کی وجوہات نہیں ہیں۔ ان تمام عوامل کا آٹیزم سے کوئی تعلق نہیں ہے۔ اور نہ ہی یہ آٹیزم کا مرض پیدا کرنے میں کوئی کردار ادا کرتے ہیں۔

(iii) آٹیزم میں مبتلا بچہ پیدا کرنے کی وجہ سے بچے کی والدہ کو برا بھلا نہیں کہنا چاہیے۔ آٹیزم کا مرض لاحق ہونے میں خواتین کا کوئی کردار نہیں ہے۔ اس لئے بچوں کے آٹیزم کے لئے ماؤں کو قصوروار نہ سمجھیں۔

(iv) اگر کسی کا ایک بچہ آٹیزم کے ساتھ پیدا ہو، تو اس کا مطلب ہرگز یہ نہیں ہے کہ دیگر تمام بچے

بھی اسی معذوری کیساتھ پیدا ہوں گے۔

(v) آٹیزم چھوت کی بیماری نہیں ہے۔کہ یہ آٹیزم میں مبتلا بچے کے بہن بھائیوں، دوسرے بچوں یا بالغ افراد کو لگ جائے۔

کیا آٹیزم کا کوئی علاج ہے؟

ابھی تک آٹیزم کا کوئی علاج دریافت نہیں ہوا۔تاہم آٹیزم کی علامات ومسائل میں کافی حد تک کمی ممکن ہے۔گزشتہ کئی سالوں سے ماہرین آٹیزم کا علاج تلاش کرنے کی کوشش کررہے ہیں۔لیکن ابھی تک کوئی ایسا علاج دریافت نہیں ہوا جو مکمل طور پر اس معذوری کے تمام اثرات کو ختم کردے۔اگرچہ آٹیزم عمر بھر کی معذوری ہے،لیکن بہت سے ایسے علاج اور طریقے موجود ہیں جن کے ذریعے سے آٹیزم سے منسلک کئی علامات ومسائل پر قابو پایا جاسکتا ہے۔

بچے پر آٹیزم کا لیبل کیوں لگایا جائے؟

اگرچہ والدین کے لئے یہ تسلیم کرنا بہت مشکل اور تکلیف دہ ہے کہ ان کے بچے کو آٹیزم ہے۔لیکن اس خوف سے کے لوگ بچے کو بیمار اور ذہنی مریض کہیں گے،اس کی بیماری کے بارے میں ڈاکٹر سے پوچھنے اور بیماری کی تشخیص سے نہیں بھاگنا چاہیے۔لیبل کے خوف سے تشخیص سے گریز کرنا بچے کے لئے بہت سے مسائل پیدا کرسکتا ہے۔اگر آٹیزم کی ابتدائی عمر میں نشاندہی ہوجائے، تو فوری طور پر علاج شروع کیا جاسکتا ہے۔تحقیق سے یہ ثابت ہوا ہے کہ ابتدائی عمر میں علاج شروع کردینے سے بچے میں بہت بہتری لائی جاسکتی ہے۔اور اس کے آٹیزم پر کافی حد تک قابو پایا جاسکتا ہے۔

5

آٹیزم کی اہم علامات کون سی ہیں؟

آٹیزم کی علامات تمام افراد میں مختلف ہوسکتی ہیں۔تاہم چند علامات جو عام طور پر تمام لوگوں میں کسی نہ کسی حد تک ظاہر ہوتی ہیں، مندرجہ ذیل ہیں۔

1۔ گفتگو اور بات چیت میں مشکل محسوس کرنا۔

2۔ لوگوں سے ملنے جلنے اور تعلق رکھنے میں مشکل محسوس کرنا۔

3- خیالات اور سوچنے سمجھنے سے متعلق مسائل کا سامنا۔

یہ علامات کے تین بنیادی گروہ ہیں، جو آٹیزم میں مبتلا تمام افراد میں کسی نہ کسی حد تک پائے جاتے ہیں۔تاہم ان بنیادی مسائل کے علاوہ چند دیگر مسائل بھی آٹیزم میں مبتلا افراد میں پائے جاتے ہیں، جو مندرجہ ذیل ہیں۔

4۔ حواس سے متعلق مسائل۔

5۔ معمولات سے محبت اور تبدیلی پر مزاحمت۔

6۔ شدید قسم کی خصوصی دلچسپیاں۔

1. گفتگو اور بات چیت سے متعلق مسائل:

آٹیزم کی ایک اہم علامت گفتگو اور بات چیت میں مشکل محسوس کرنا ہے۔آٹیزم میں مبتلا بعض افراد بالکل گفتگو نہیں کر سکتے۔کچھ لوگ صرف چند الفاظ بول سکتے ہیں۔کچھ لوگ بہت تھوڑی گفتگو کر سکتے ہیں۔جبکہ بعض دیگر افراد صحیح و واضح گفتگو کر سکتے ہیں۔

صحیح اور واضح گفتگو کرنے والے بچوں میں بھی کئی طرح کے مسائل پائے جاتے ہیں۔کچھ بچے ایک ہی

لفظ یا جملے کو بار بار دہراتے رہتے ہیں۔اس مرض کو ایکولیلیا (Echolalia) بھی کہتے ہیں۔کچھ بچے ایک ہی موضوع پر گھنٹوں بات کرتے رہتے ہیں۔وہ اس بات کو نہیں سمجھ سکتے کہ دوسرے لوگ ایک ہی موضوع پر ان کی اتنی لمبی گفتگو سے تنگ آ گئے ہیں۔آٹیزم میں مبتلا کچھ افراد عجیب وغریب اور غیر معمولی آوازیں بھی نکالتے ہیں۔جبکہ چند دیگر عجیب وغریب جملے استعمال کرتے ہیں یا عجیب گفتگو کرتے ہیں

آٹیزم میں مبتلا بعض افراد ایسے بھی ہیں کہ جو کچھ جملے رٹ لیتے ہیں،مگر ان کے معنی کو نہیں جانتے۔یعنی کسی فلم،کارٹون،کہانی،یا کسی کتاب سے کافی سارے جملے یاد کر کے ان کو بولتے ہیں،مگر اس کے معنی اور مقصد سے بے خبر ہوتے ہیں۔

<u>آٹیزم میں مبتلا افراد کو گفتگو کے حوالے سے مندرجہ ذیل مسائل کا سامنا ہو سکتا ہے:</u>

(i) اپنی ضروریات بتانے میں مشکل محسوس کرنا: یعنی واضح طور پر یہ نہیں بتا پاتے کہ انہیں کسی چیز کی ضرورت ہے یا یہ کہ وہ کیا چاہتے ہیں،وغیرہ۔

(ii) گفتگو کے دوران چہرے کے تاثرات وجسمانی حرکات کے صحیح استعمال میں مشکل محسوس کرنا

(iii) دوسرے لوگوں کے چہرے کے تاثرات وجسمانی حرکات کو سمجھنے میں مشکل محسوس کرنا: یعنی انہیں دوسرے لوگوں کی خوشی،غم،افسردگی،گھبراہٹ ، پریشانی،تکلیف وغیرہ کا اندازہ لگانے اور شناخت کرنے میں دشواری ہوتی ہے۔

(iv) صورتحال کے مطابق آواز کے استعمال میں مشکل محسوس کرنا: مثلاً غصے اور لڑائی کے عالم میں عام طور پر لوگوں کی آواز بلند وسخت ہو جاتی ہے۔جبکہ خوشی واطمینان کے وقت آواز میں نرمی آجاتی ہے۔لیکن آٹیزم میں مبتلاء افراد کو صورتحال اور جذبات کے مطابق آواز کے اتار

چڑھاؤ میں مشکل پیش آتی ہے۔ممکن ہے کہ وہ غصے کی بات کو نرمی سے کریں اور نرمی کی بات اونچی آواز میں کریں۔

(v) دوسرے لوگوں کی آواز کے اتار چڑھاؤ کو سمجھنے میں مشکل محسوس کرنا۔

(vi) مذاق کرنے میں مشکل محسوس کرنا۔

(vii) دوسرے افراد کی نقل اتارنے میں مشکل محسوس کرنا۔

(viii) مذاق سمجھنے میں مشکل کا سامنا۔

(ix) لفظوں کے معنی سمجھنے میں دشواری۔

(x) محاورے سمجھنے یا استعمال کرنے میں دشواری۔

(xi) اپنے جذبات واحساسات کا اظہار کرنے میں مشکل محسوس کرنا۔

(xii) گفتگو کا آغاز کرنے میں مشکل محسوس کرنا: یعنی کسی سے بات چیت کرنے میں پہل کرنا یا بات چیت شروع کرنا، آٹیزم میں مبتلا افراد کے لئے مشکل ہوتا ہے۔

(xiii) گفتگو جاری رکھنے میں مشکل محسوس کرنا۔

(xiv) گفتگو و بات چیت کے آداب سے ناواقفیت۔

<u>گفتگو و بات چیت سے متعلق مسائل پر قابو پانے کے لئے چند اہم تجاویز:</u>

(i) <u>آسان زبان استعمال کریں:</u>

سادہ و آسان زبان استعمال کریں، جسے بچہ آسانی سے سمجھ سکے۔مشکل الفاظ کا استعمال نہ کریں۔

(ii) محاورے استعمال نہ کریں:

چونکہ بچوں کو محاورے سمجھنے میں دشواری ہوتی ہے، اس لئے کوشش کریں کہ اس سے گریز کریں۔

(iii) ذو معنی الفاظ استعمال نہ کریں:

ایسے الفاظ جن کے ایک سے زائد معنی ہو سکتے ہیں، ان کے استعمال سے گریز کریں۔

(iv) واضح الفاظ استعمال کریں:

مبہم الفاظ یا غیر واضح گفتگو سے پرہیز کریں۔ مثال کے طور پر بچے کو اگر یہ کہا جائے کہ: ''ہم پارک چلیں گے''، تو بچے کو یہ سمجھنے میں دشواری ہوگی کہ کب چلیں گے۔ اس طرح وہ ذہنی دباؤ اور پریشانی کا شکار ہو سکتا ہے۔ مندرجہ بالا جملے کی بجائے اگر یوں کہا جائے کہ: ''ہم رات کے کھانے کے بعد پارک چلیں گے''، تو اس سے بچے پر آپ کی گفتگو واضح ہو جائے گی۔ واضح گفتگو کرنے اور وقت کا تعین کرنے سے بچے کو سمجھنے میں آسانی ہو جاتی ہے اور وہ ذہنی دباؤ سے بچ جاتا ہے۔

(v) مختصر گفتگو کریں:

لمبے جملے استعمال نہ کریں۔ کوشش کریں کہ چھوٹے سے چھوٹا جملہ استعمال کریں۔

(vi) بچے کی توجہ حاصل کریں:

گفتگو شروع کرنے سے پہلے بچے کی توجہ حاصل کرنے کی کوشش کریں (مثلاً اس کے کندھے پر ہاتھ رکھیں یا اس کا نام لیں تا کہ وہ آپ کی طرف متوجہ ہو جائے)۔

(vii) گفتگو کے آغاز میں بچے کا نام استعمال کریں:

بچے کو اس کا نام لے کر پکاریں، تا کہ یہ واضح ہو جائے کہ آپ اس سے بات کر رہے ہیں۔

(viii) بچے کے جواب کا انتظار کریں:

آٹیزم میں مبتلا بچے دیگر بچوں کی نسبت دوسروں کی گفتگو سمجھنے اور اس کا جواب دینے میں زیادہ وقت لگاتے ہیں۔اس لیے جب آپ بچے سے بات کریں، تو اسے عام بچوں کی نسبت زیادہ وقت دیں۔ تا کہ بچہ آپ کی بات کو سمجھ کر، اپنے ذہن میں آپ کی بات کا جواب سوچ کر، پھر کچھ دیر میں آپ کو جواب دے سکے۔

(xi) واضح ہدایات دیں:

بچے کو ہدایات واضح انداز میں دیں۔مثلاً بجائے یہ کہنے کہ: ''بچوں! کھانا کھالو''۔ یوں کہیں کہ: ''احمد! کھانا کھالو''۔

(x) ہدایات دیتے وقت ترتیب کا خیال رکھیں:

آٹیزم میں مبتلا افراد کو یہ مسئلہ بھی درپیش ہو سکتا ہے کہ وہ دی گئی ہدایات کو خود ہی ترتیب دے لیں۔اس لیے انہیں کام بتاتے وقت اسی ترتیب سے بتائیں، جس ترتیب سے کام کرنا ہو۔ (مثلاً اگر یہ کہا جائے کہ ''مہمان آنے والے ہیں، نہا دھو کر تیار ہو جاؤ۔اور اپنے کھلونے بھی ڈبے میں ڈالو۔سی ڈی دراز میں رکھو اور کپڑے الماری میں ٹانگو۔لیکن پہلے کھانا کھالو'')۔

اس طرح ہدایات دینے سے بچہ ذہنی دباؤ کا شکار ہو سکتا ہے۔اور ممکن ہے کہ وہ کچھ کام بھول جائے یا صحیح طور پر انجام نہ دے پائے۔اس لئے بہتر ہے کہ اسی ترتیب سے ہدایات دیں، جس ترتیب سے واقع ہونی ہیں۔مثلاً اوپر دی گئی ہدایات کو اس انداز میں بھی کہا جا سکتا ہے

کہ: ''احمد! پہلے کھانا کھالو۔ پھر اپنے کھلونے ڈبے میں ڈالو اور اپنی گیم کی سی ڈی دراز میں رکھو۔ پھر اپنے کپڑے الماری میں ٹانگو۔ پھر نہا کر تیار ہو جاؤ۔ مہمان آنے والے ہیں۔''

(xi) <u>ایک وقت میں ایک ہدایت دیں:</u>

بچے کو ایک ساتھ بہت سے کام بتانے سے گریز کریں۔ یعنی ایک ہی وقت میں بہت سی ہدایات نہ دیں۔ بچے کو ایک وقت میں ایک یا دو کام بتائیں۔ جب وہ اس کام سے فارغ ہو جائے، تو دوسرا کام بتائیں۔ جیسا کہ اوپر بیان کی گئی مثال میں ایک ہی وقت میں کئی ہدایات دی گئی ہیں۔ ایسا کرنے سے بچے کے لئے اتنی باتوں کو یاد رکھنا مشکل ہو سکتا ہے۔ بہتر یہ ہے کہ بچے کو ایک ایک کر کے کام بتائیں۔ مثلاً یوں کہیں: ''احمد بیٹا! کھانے کا ٹائم ہو گیا ہے۔ کھانا کھالو۔'' جب بچہ کھانا کھا چکے، تو دوسری ہدایت دیں کہ: ''کھلونے ڈبے میں ڈالو''۔ اور اسی طرح ایک ایک کر کے ہدایت دیں۔

(xii) <u>بچے کو مثبت انداز میں ہدایات دیں:</u>

یعنی یہ بتانے کی بجائے کہ اسے کیا کام نہیں کرنا چاہیے، یہ بتائیں کہ اسے کیا کرنا چاہیے ۔ مثال کے طور پر، اگرچہ یہ بھی کہا جا سکتا ہے کہ: ''احمد! کیلے کا چھلکا نیچے نہ پھینکو۔'' لیکن آٹیزم کا شکار بچوں کے لئے بہتر طریقہ یہ ہے کہ بچے سے کہیں کہ: ''احمد! کیلے کا چھلکا ڈسٹ بن میں پھینکو''۔ یعنی بے جا روک ٹوک کی بجائے بچے کو واضح بتایا جائے کہ اسے کیا کرنا چاہیے۔

(xiii) <u>بچے کو ''پہلے یہ کرو، پھر وہ ملے گا'' کا تصور متعارف کروائیں:</u>

یعنی بچے سے کوئی بھی خاص کام کروانا مقصود ہو، یعنی پڑھائی، کھانا، نہانا وغیرہ، تو بچے

سے کہیں کہ 'پہلے یہ کام کرو پھر تمہاری پسند کی چیز ملے گی'۔ مثلاً: ''پہلے کھانا ختم کرو، پھر وڈیو گیم ملے گی۔'' یا یوں کہیں کہ: ''پہلے پڑھائی، پھر چاکلیٹ۔''

(xiv) بچے سے انتخاب کروائیں:

مثال کے طور پر اگر کھیلنے کا وقت ہے، تو بچے سے کہیں کہ اپنے پسندیدہ کھیلوں یا چیزوں میں سے ایک کا انتخاب کرے۔ یعنی گاڑیاں، کمپیوٹر، ویڈیو گیم، کارٹون میں سے ایک کا انتخاب کرو کہ اس وقت کیا کرنا ہے۔

اسی طرح کھانے کی اشیاء جو گھر میں موجود ہوں، ان میں سے ایک کا انتخاب کروالیں۔ مثلاً بچے سے کہیں کہ ان چیزوں یعنی بسکٹ، چپس، سینڈوچ، ٹافی میں سے ایک چن لو، کون سی چیز کھانی ہے۔

(xv) ''کام ختم'' کے تصور کو متعارف کروائیں:

مثلاً جب کوئی سرگرمی، ختم ہو یا بچے کو جو کام دیا ہے وہ اس سے فارغ ہو جائے تو اسے ''کام ختم'' کا کارڈ دکھائیں۔ یا کہہ دیں: ''کام ختم۔''

یہ تمام تجاویز آٹیزم کا شکار بچے کی زندگی میں بہت اہم کردار ادا کر سکتی ہیں۔ صحت مند بچے بہت سے کام قدرتی طور پر خود بخود سیکھ جاتے ہیں۔ لیکن آٹیزم میں مبتلا بچوں کو بہت سی چیزیں سکھانی پڑتی ہیں۔ جو بعد میں جا کر ان کے لئے فائدہ مند ہوتی ہیں اور اچھی زندگی گزارنے میں مددگار ثابت ہوتی ہیں۔ بہت سے روزمرہ زندگی کے کام جو ہم معمول میں کر لیتے ہیں، یعنی اپنی پسند کی اشیاء کا انتخاب کرنا، ضروری کاموں کو پہلے کرنا، غیر اہم کاموں کو بعد میں کرنا، ایک کام مکمل کر کے پھر دوسرا کام کرنا وغیرہ۔

جب کہ آٹیزم میں مبتلاء بچے یہ سب کرنے میں مشکل محسوس کرتے ہیں۔اس لئے انہیں اس بات کی تربیت دینا ضروری ہے کہ پہلے ایک کام کو ختم کرلو۔ جب ختم ہوجائے، پھر دوسرا شروع کرو۔اہم کام اور غیر اہم کام میں انتخاب کرو، وغیرہ۔

2- سماجی تعلقات سے متعلق مسائل :

آٹیزم میں مبتلا لوگوں کو سماجی تعلقات میں بھی کسی نہ کسی حد تک مشکل کا سامنا ہوتا ہے۔ان میں سے کچھ افراد تو دوسروں سے ملنے جلنے کی بالکل کوشش نہیں کرتے اور اکیلے رہنا پسند کرتے ہیں۔جبکہ چند دیگر افراد کو دوسرے لوگوں سے بات چیت کرنے اور تعلقات بنانے کا شوق تو ہوتا ہے، مگر انہیں لوگوں سے ملنے جلنے اور بات چیت کرنے کا طریقہ نہیں آتا۔

آٹیزم میں مبتلا افراد کو جن کاموں میں مشکل محسوس ہوتی ہے، وہ مندرجہ ذیل ہیں۔

(i) دوسرے لوگوں کے جذبات واحساسات سمجھنے میں مشکل محسوس کرنا۔

(ii) اپنے جذبات واحساسات کا اظہار کرنے میں مشکل محسوس کرنا۔

(iii) اپنی خوشی وغم کو دوسروں کے ساتھ بانٹنے میں مشکل محسوس کرنا۔

(iv) دوسروں کے ساتھ کھیلنے میں مشکل محسوس کرنا:

آٹیزم میں مبتلا بچے عموماً اپنے ہم عمر بچوں کے ساتھ کھیلنا پسند نہیں کرتے۔وہ یا تو اپنے سے کم یا زیادہ عمر کے بچوں کے ساتھ کھیلنا پسند کرتے ہیں۔یا پھر بڑوں کے ساتھ رہنا پسند کرتے ہیں۔کچھ بچے اکیلے کھیلنے کو ترجیح دیتے ہیں۔یعنی کار، گڑیا، بندوق، یا دیگر کھلونوں سے اکیلے ہی کھیلنا۔

(v) دوست بنانے میں مشکل محسوس کرنا۔

(vi) اپنی باری کا انتظار کرنے میں مشکل محسوس کرنا۔

یعنی لڈو، کرکٹ، یا ایسے کھیل جن میں اپنی باری کا انتظار کرنا پڑے، آٹیزم میں مبتلا بچے ایسے کھیل کھیلنا پسند نہیں کرتے۔

(vii) مل جل کر کھیلنے یا مل بانٹ کر کھانے میں مشکل محسوس کرنا:

آٹیزم میں مبتلا بچے ممکن ہے کہ دوسرے بچوں کو اپنا کھلونا یا کھانے کی چیز نہ دیں۔ جب کہ دوسرے کے ہاتھ سے کھلونا یا کھانے کی چیز چھین لیں۔

(viii) دوسروں کے نقطہ نظر کو سمجھنے میں مشکل محسوس کرنا۔

(ix) سماجی قوانین سمجھنے میں مشکل کا سامنا:

یعنی آٹیزم میں مبتلا بچے یہ نہیں جانتے کہ کس صورتحال میں اور کس جگہ پر کیسے برتاؤ کرنا چاہیے۔ جیسا کہ مسجد میں بیٹھنے کے کیا آداب ہوتے ہیں، مہمانوں کے سامنے کیسے پیش آنا چاہیے، بازار میں کس طرح پیش آنا چاہیے، شادی بیاہ میں شرکت کا کیا طریقہ ہے، وغیرہ۔

(x) گفتگو کے آداب سے ناواقفیت:

آٹیزم میں مبتلا افراد گفتگو کے آداب سے نا واقف ہو سکتے ہیں۔ یعنی گفتگو کے دوران دوسرے شخص کے کتنا قریب کھڑے ہونا چاہیے۔ اور کس طرح بات کرنی چاہیے، وغیرہ۔ ممکن ہے کہ وہ گفتگو کرنے والے شخص کے انتہائی نزدیک کھڑے ہو جائیں، کہ بات کرنے میں دشواری ہونے لگے۔ یا ممکن ہے کہ وہ ایک ہی سوال بار بار دہراتے رہیں۔ یا پھر

دوسرے شخص کو اپنی طرف متوجہ کرنے کے لئے اس کا بازو کھینچ کر یا دھکا دے کر اپنی طرف متوجہ کریں۔

انکی محدود سماجی سمجھ بوجھ کی وجہ سے ممکن ہے کہ دوسرے لوگ ان کے رویے و حرکات کو غلط و نامناسب تصور کریں۔ مثال کے طور پر اگر کسی شخص کو شدید درد ہو، یا گہری چوٹ لگ جائے، تو ممکن ہے کہ آٹیزم میں مبتلا بچہ اسے دیکھنے کے باوجود آرام سے کھیلتا رہے۔ وہ اٹھ کر دوسرے سے ہمدردی کا اظہار بھی نہ کرے اور نہ ہی کوئی مدد کرے۔ مگر بچے کے اس طرزِ عمل کا یہ مطلب ہرگز نہیں ہے کہ بچہ بے حس ہے اور اسے کسی کی تکلیف کا احساس نہیں۔ بلکہ بچے کے اس رویے کی کئی وجوہات ہوسکتی ہیں۔ مثلاً یہ کہ بچے کو دوسرے کے جذبات و احساسات کا پتہ ہی نہیں چلتا کہ کون کب دکھی ہے، کب خوش ہے اور کب تکلیف میں ہے۔ دوسری بات یہ ہے کہ بچے کو ہمدردی کرنے کا طریقہ بھی نہیں آتا۔ اسے یہ معلوم ہی نہیں ہوتا کہ اگر کسی سے ہمدردی کرنی ہو، تو کون سے جملے بولیں اور کیا مدد کریں۔

<u>سماجی تعلقات سے متعلق مسائل پر قابو پانے کے لئے چند اہم تجاویز:</u>

(i) <u>مشترکہ توجہ:</u>

ایسے کھیل متعارف کرائیں جس میں بچے کو دوسرے لوگوں سے باپ چیت اور تعاون کرنا پڑے۔ یعنی جس میں مل جل کر کھیلنا پڑے۔ مثلاً سرف کے پانی سے بلبلے بنانا، کرکٹ کھیلنا وغیرہ۔

(ii) <u>بچے کے قریب بیٹھ کر کھیلنا:</u>

اگر آٹیزم میں مبتلا بچہ کسی دوسرے کے ساتھ کھیلنا پسند نہ کرے، تو بچے کے قریب بیٹھیں،

جہاں وہ آپ کو دیکھ سکے اور جیسے وہ کھیل رہا ہو، اسکے کھیل کی نقل کریں۔ اس طرح آہستہ آہستہ اسے دوسرے لوگوں کو اپنے اردگرد برداشت کرنے کی عادت ہو جائے گی اور بتدریج دوسروں کو اپنے کھیل میں شامل کرنے کی بھی عادت ہو جائے گی۔

(iii) بچوں کے کھیل میں شامل ہونا:

بچہ جو کھیل بھی کھیلنا پسند کرتا ہو (مثلاً کاروں سے کھیلنا یا کسی کھلونے یا پانی سے کھیلنا)، اس کے کھیل میں شامل ہو جائیں۔ اگر وہ بہن بھائیوں کے ساتھ کھیلنا پسند نہ کرے، تو شروع میں والدین بچے کیساتھ کھیلیں۔ بعد میں جب بچہ والدین کو اپنے کھیل میں برداشت کرنے کا عادی ہو جائے، تو آہستہ آہستہ کچھ عرصے بعد بہن بھائیوں کو بھی کھیل میں شامل کیا جا سکتا ہے۔

(iv) اپنی باری کا انتظار کرنا:

بچے کو اپنی باری کا انتظار کرنے کی عادت ڈالیں۔ مثال کے طور پر کھیل کے دوران، کھانے کے وقت یا کسی بھی دیگر سرگرمی کے دوران، باری کی عادت ڈالیں۔ مثلاً جب بچے کی باری آئے، تو کہہ سکتے ہیں کہ: ''اب احمد کی باری'' اور جب آپکی باری آئے، تو کہہ سکتی ہیں کہ: ''اب مما کی باری'' وغیرہ۔

(v) بچے کو پرسکون ہونے کے لئے وقت دیں:

آٹیزم میں مبتلا بچے لوگوں سے ملنے جلنے میں مشکل محسوس کرتے ہیں۔ انہیں کچھ وقت اکیلا رہنے کی ضرورت ہوتی ہے، تاکہ وہ پرسکون ہو سکیں۔ لہذا لوگوں سے بات چیت کے بعد کچھ دیر انہیں اکیلے رہنے کے لئے وقت دیں۔

(vi) اپنے جذبات واحساسات کا اظہار الفاظ میں کریں:

اپنی خوشی وغم کا اظہار چہرے کے تاثرات کے ساتھ ساتھ الفاظ میں بھی کریں۔ مثال کے طور پر اگر آپ بچے کے کسی کام کی وجہ سے خوش ہوں، تو ایک مسکراہٹ کے ساتھ اسے بتائیں کہ آپ اس کے اس کام سے خوش ہیں۔ بچے کو دوسرے کے چہرے کے تاثرات پڑھنے اور دوسرے کے جذبات سمجھنے میں دشواری ہوئی ہے۔ اس لئے جذبات کو الفاظ میں واضح کریں۔ تاکہ بچے کو جذبات کے اظہار کا صحیح ومناسب طریقہ معلوم ہو۔ نیز یہ بھی پتہ چلے کہ دوسرے لوگ بھی جذبات واحساسات رکھتے ہیں۔

(vii) بچے کو اس کے جذبات کا اظہار کرنے میں مدد دیں:

مثال کے طور پر اگر آپ بچے کو اس کی پسند کا کھلونا دیں، یا پسند کی کھانے کی چیز دیں، تو اس سے پوچھیں کہ کیا وہ اپنی پسند کی چیز پانے پر خوش ہے۔ یا پھر بچے کو اپنے جذبات کا اظہار کرنے کا مناسب طریقہ سکھانے کے لئے، یہ بھی کہا جاسکتا ہے کہ: ''احمد کو اس کی پسند کی کار ملی۔ احمد بہت خوش ہے''۔

(viii) سماجی قوانین واضح کریں:

آٹیزم میں مبتلا بچے مشاہدے سے، یعنی دوسروں کو دیکھ کر خود بخود سیکھنے میں مشکل محسوس کرتے ہیں۔ اس لیے انہیں لوگوں میں اٹھنے بیٹھنے، یا کسی خاص صورت حال میں پیش آنے کے طریقے واضح کرنے پڑتے ہیں۔ مثلاً مسجد میں کیسے بیٹھنا چاہیے۔

(ix) بچے کو شادی بیاہ اور دیگر تقاریب میں جانے، لوگوں سے ملنے اور لوگوں میں بیٹھنے کی عادت ڈالیں:

آٹیزم میں مبتلا اکثر بچے لوگوں سے ملنے جلنے سے گھبراتے ہیں اور شادی بیاہ، سالگرہ یا دیگر تقاریب پر جانا پسند نہیں کرتے۔ اکثر بچے ایسی جگہوں پر بہت زیادہ رونا پیٹنا، چیخیں مارنا یا شور مچانا شروع کر دیتے ہیں۔ اسی وجہ سے والدین بچوں کو ایسی تقاریب میں لے کر ہی نہیں جاتے۔ لیکن ایسا کرنے سے بچے اور زیادہ حساس ہو جاتے ہیں اور لوگوں سے میل جول کی برداشت مکمل طور پر ختم ہو سکتی ہے۔ لہذا بچوں کو دوسرے لوگوں میں گھلنے ملنے کی، نیز لوگوں کو اپنے اردگرد برداشت کرنے کی عادت ڈالیں۔ اس کے لئے شروع میں بچے کو پانچ منٹ کے لئے بازار، سالگرہ یا شادی بیاہ کی تقریب میں لے کر جائیں۔ پانچ منٹ کے بعد بچے کی ماں یا باپ بچے کے ساتھ گھر واپس آ جائے۔ جب بچے کو پانچ منٹ لوگوں میں آرام سے بیٹھنے کی عادت پختہ ہو جائے، تو بتدریج وقت بڑھاتے جائیں۔ پانچ منٹ سے دس منٹ، پھر پندرہ منٹ اور اسی طرح وقت بڑھاتے جائیں۔ اس طرح بچے میں لوگوں سے میل جول کی صلاحیت پیدا کی جا سکتی ہے۔

ممکن ہے کہ آٹیزم میں مبتلا بچے کوئی بھی اصول سیکھنے میں عام بچوں کی نسبت زیادہ وقت لگائیں۔ لہذا والدین کو ہمت نہیں ہارنی چاہیے۔ یہ بچے برے نہیں ہوتے اور ذہنی طور پر معذور بھی نہیں ہوتے۔ تاہم ان کے سیکھنے کے طریقے، دیگر بچوں کی نسبت مختلف ہوتے ہیں۔ اور یہ بچے سیکھنے میں کچھ زیادہ وقت لگا سکتے ہیں۔

3. خیالات اور سوچنے سمجھنے سے متعلق مسائل:

آٹیزم میں مبتلا افراد سوچنے، سمجھنے سے متعلق بہت سے مسائل کا شکار ہو سکتے ہیں۔ ان میں سے بعض افراد اپنے اردگرد کی دنیا کو بالکل نہیں سمجھ پاتے۔ وہ لوگوں کی سوچ یا رائے کا بالکل اندازہ نہیں لگا پاتے۔ نہ کسی کو پرکھ سکتے ہیں، نہ کسی کو سمجھ سکتے ہیں۔

آٹیزم میں مبتلا افراد کو خیالات اور سوچنے سمجھنے سے متعلق مندرجہ ذیل مسائل درپیش ہو سکتے ہیں۔

(i) تصوراتی و خیالی کھیل کھیلنے میں مشکل محسوس کرنا:

مثلاً دیکھنے میں آیا ہے کہ عام صحت مند بچے، کبھی استاد کی نقل اتار کر کھیل کھیل میں استاد بنے ہوئے ہوتے ہیں۔ کبھی ڈاکٹر بن جاتے ہیں، تو کبھی کسی کارٹون یا ڈرامے کی نقل کر رہے ہوتے ہیں۔ اسی طرح وہ مختلف اشیاء مثلاً کھلونوں والی بندوق کو اصلی بندوق تصور کر کے دشمن پر حملہ کر رہے ہوتے ہیں، تو کبھی گڑیا کو بچہ تصور کر کے اسے جھوٹ موٹ کا کھانا کھلا رہے ہوتے ہیں۔ ان تصوراتی سرگرمیوں سے بچے کی ذہنی صلاحیتیں نشوونما پاتی ہیں۔ اور اس کی سوچنے سمجھنے کی صلاحیت پختہ ہوتی ہے۔ مگر آٹزم میں مبتلا بچے، اس قسم کے تصوراتی کھیل نہیں کھیل پاتے۔

(ii) خطرے سے عدم آگاہی یا خطرے کی سمجھ نہ ہونا:

آٹیزم میں مبتلا بچہ ممکن ہے کہ ابلتے ہوئے پانی کے برتن کو اٹھا لے، یہ سوچے بغیر کہ گرم پانی اسے جلا سکتا ہے۔ اسی طرح ممکن ہے کہ وہ مصروف ترین (یعنی ٹریفک والی) سڑک کے درمیان میں دوڑنے لگے، یہ سوچے بغیر کہ اسے حادثہ پیش آ سکتا ہے، یا وہ کسی کار کے نیچے آ کر کچلا بھی جا سکتا ہے۔ ایسا بھی ممکن ہے کہ آٹیزم میں مبتلا بچہ، کسی دوسرے کو کوئی بھاری

چیز دے مارے، یا کسی تیز دھار چیز سے ماردے۔ یہ سوچے سمجھے بغیر کہ یہ چیز دوسرے کو نقصان دے سکتی ہے، یعنی اسے زخمی کرسکتی ہے۔

یعنی ان بچوں کو پتہ ہی نہیں چلتا کہ کون سی چیز خطرناک اور نقصان دہ ہے، اور کون سی چیز فائدہ مند۔ اس لئے وہ خود کو یا دوسروں کو نقصان پہنچانے کا سبب بن سکتے ہیں۔ مگر اس میں انکا کوئی قصور نہیں ہوتا۔ وہ جان بوجھ کر ایسا نہیں کرتے، بلکہ ناسمجھی میں کرسکتے ہیں۔

(iii) دوسرے لوگوں کے رویے کو سمجھنے میں مشکل محسوس کرنا: یعنی رویوں کے بارے میں اندازہ لگانے میں ناکامی۔

(iv) آنے والی صورتحال کا اندازہ لگانے میں مشکل محسوس کرنا۔

(v) تفصیلات پر توجہ، مگر مجموعی صورتحال سمجھنے میں مشکل محسوس کرنا:

آٹیزم میں مبتلا بعض افراد کسی چیز کی تفصیلات پر تو بہت توجہ دیتے ہیں، مگر مجموعی صورتحال کو بالکل نہیں سمجھتے۔ جیسا کہ دیکھنے میں آیا ہے کہ آٹیزم میں مبتلا بچہ کار سے کھیلنے کی بجائے، اس کے پہیے کو غور سے دیکھتا رہتا ہے، اور بعض اوقات کار کی بجائے اس کے پہیے سے کھیلتا ہے۔

(vi) تبدیلی برداشت کرنے اور تبدیلی کے لئے تیار رہنے میں دشواری۔

(vii) نئی اور ناواقف صورتحال سے نمٹنے میں مشکل محسوس کرنا۔

(viii) غیر متوقع صورتحال سے نمٹنے میں مشکل محسوس کرنا۔

(ix) مستقبل کے لئے منصوبے بنانے میں مشکل محسوس کرنا:

سوچنے سمجھنے کی صلاحیتوں میں دشواری کے باوجود آٹیزم میں مبتلا چند افراد باکمال تخلیقی اور تصوراتی صلاحیتوں کے مالک ہوسکتے ہیں۔ مثال کے طور پر اگر کسی کو موسیقی، آرٹ یا لکھنے

کے ہنر میں دلچسپی ہو تو ممکن ہے کہ وہ ایک مشہور موسیقار، پینٹر یا مصنف بن جائے۔

<u>خیالات اور سوچنے سمجھنے سے متعلق مسائل پر قابو پانے کے لئے چند اہم تجاویز:</u>

(i) روزانہ کے لئے اور ہفتہ وار شیڈول بنائیں۔

(ii) آنے والی یعنی کہ ممکنہ تبدیلیوں کے لئے بچے کو پہلے ہی آگاہ کر دیں۔

(iii) تبدیلی بتدریج متعارف کرائیں۔

(iv) تبدیلی متعارف کرانے کے لئے بصری معاونات یا ٹائم ٹیبل استعمال کریں۔

(v) بچے کے خیالات اور سوچنے سمجھنے کی صلاحیت کو بہتر بنانے میں مدد دیں:

☆ اس کے لئے بچے کو کسی بھی صورتحال یا مسئلہ کے ایک سے زیادہ حل سوچنے کو کہیں۔

☆ بچے کو یہ واضح کریں کہ کس طرح ایک چیز کئی طریقوں سے استعمال کی جاسکتی ہے ۔مثلاً پلنگ سونے کے لئے بھی استعمال کیا جاسکتا ہے اور بیٹھنے کے لئے بھی۔اسی طرح باغ کو کھیلنے کے لئے بھی استعمال کر سکتے ہیں اور چلنے پھرنے کے لئے بھی۔ نیز دعوت وتقریبات وغیرہ کا انتظام بھی باغ میں کیا جاسکتا ہے۔

☆ بچے کو تصوراتی کھیل کھلائیں۔مثلاً اگر بچہ گڑیا کے ساتھ کھیل رہا ہو، تو آپ گڑیا کی شادی کی تقریب منعقد کر سکتے ہیں۔یا پھر اگر بچہ کاروں سے کھیلتا ہو، تو کھلونوں والی کاروں کی ریس کا مقابلہ کروا سکتے ہیں۔

4۔ <u>حواس سے متعلق مسائل:</u>

آٹیزم میں مبتلا افراد میں بہت سی حسی دشواریاں بھی پائی جاتی ہیں۔دیکھنے، سننے، چکھنے، سونگھنے، چھونے

اور توازن سے متعلق مختلف طرح کے مسائل و مشکلات کا شکار ہو سکتے ہیں۔ بچہ انتہائی حساس یا بالکل بے حس ہو سکتا ہے۔ یعنی بعض بچوں کی سننے وغیرہ کی حس ضرورت سے زیادہ تیز ہوتی ہے، جبکہ بعض بچوں کی یہ حس بہت کمزور ہوتی ہے۔

آٹیزم میں مبتلا بچے کو جو ممکنہ حسی مسائل ہو سکتے ہیں وہ مندرجہ ذیل ہیں:

(i) <u>جسمانی توازن برقرار رکھنے میں دشواری اور اپنے جسم کے بارے میں عدم آگاہی:</u>

الف۔ دائرے میں گھومنا، آگے پیچھے ہلتے رہنا، چکر کھانا، ہاتھوں کو جھٹکتے رہنا وغیرہ۔

ب۔ دوسروں کے انتہائی نزدیک کھڑے ہونا (یعنی بچے یہ نہیں جانتے کہ کسی بھی شخص سے بات چیت کرتے ہوئے تھوڑا سا فاصلہ رکھنا ضروری ہے)۔

ج۔ دوسرے لوگوں سے ٹکرا جانا۔

د۔ کمروں میں چلنے میں دشواری (یعنی ایک کمرے سے دوسرے کمرے میں جانے میں مشکل کا سامنا۔ نیز فرنیچر سے بچ کر گزرنے میں مشکل محسوس کرنا)۔

ر۔ جسمانی مہارت کے کاموں میں مشکل محسوس کرنا (مثلاً اپنی شرٹ کے بٹن بند کرنا یا جوتے کے تسمے باندھنا، ان بچوں کے لئے مشکل ہو سکتا ہے)۔

(ii) <u>سننے کی حس یا آواز سے متعلق مسائل:</u>

الف۔ چند مخصوص آوازوں کے سننے پر گھبراہٹ کا اظہار۔

ب۔ کبھی کبھار آوازوں پر بالکل توجہ نہ دینا۔ یعنی کبھی کبھار ایسا محسوس ہوتا ہے کہ بچہ سن ہی نہیں سکتا۔ بہرا ہے۔

ج۔ اونچی آوازوں، شور غل اور ہجوم والی جگہوں کو ناپسند کرنا۔

د۔ اچانک اور غیر متوقع آوازوں کو ناپسند کرنا، جیسے کتے کا بھونکنا وغیرہ۔

ر۔ تیز یا مسلسل آواز کو ناپسند کرنا۔

س۔ مندرجہ بالا کے برعکس کچھ بچے شور وغل والی جگہوں کو پسند کرتے ہیں۔ اور خود بھی شور مچانا پسند کرتے ہیں۔ ایسے بچے دروازے کو پٹاخ کر کے بند کرنا یا چیزوں کو گرا کر ان کی آواز سننا پسند کرتے ہیں۔

ق۔ عام افراد ناپسندیدہ آوازوں پر توجہ نہیں دیتے۔ نیز شور وغل یا جو آواز پسند نہ آئے، اس سے بے توجہی کر کے اپنا کام جاری رکھ سکتے ہیں۔ مگر آٹیزم میں مبتلا افراد ایسا نہیں کر سکتے۔

(iii) <u>دیکھنے کی حس سے متعلق مسائل:</u>

الف۔ کچھ افراد روشنی کی شعاعوں سے کھیلتے ہیں۔

ب۔ پھینکنے اور پکڑنے (catch and throw) میں مشکل محسوس کرنا۔

ج۔ آنکھوں کے آگے انگلیوں کو جھاڑنا یا ہلانا۔

د۔ روشنی کی ایک خاص سطح یا درجہ کو برداشت نہ کر سکنا۔

ر۔ عام افراد ارد گرد نظر آنے والی بے شمار چیزوں پر توجہ کئے بغیر اپنا کام جاری رکھ سکتے ہیں۔ مگر آٹیزم میں مبتلا افراد، ارد گرد نظر آنے والی بہت ساری چیزوں میں الجھ کر رہ جاتے ہیں۔ اور کسی بھی کام پر توجہ مرکوز نہیں کر پاتے۔ مثلاً چلتے پھرتے لوگ، دیوار پر لگی گھڑی، چلتا ہوا پنکھا، میز پڑی ہوئی بے شمار اشیاء، بیڈ شیٹ کا رنگ اور ڈیزائن وغیرہ۔

(iv) <u>چھونے کی حس سے متعلق مسائل:</u>

الف۔ آٹیزم میں مبتلا بعض افراد بالکل پسند نہیں کرتے کہ انہیں ہاتھ لگایا جائے۔

ب۔ کچھ بچوں کو برش کرنے ، بال دھونے ، ناخن کاٹنے اور کپڑے پہننے میں بھی، الجھن اور دشواری کا سامنا ہوتا ہے۔

ج۔ کچھ لوگ صرف ایک مخصوص قسم کے کپڑے پہننا پسند کرتے ہیں۔

د۔ بعض لوگ ہاتھوں اور پیروں پر کسی چیز کو پہننا پسند نہیں کرتے۔

ر۔ کچھ بچے دوسروں کو بہت مضبوطی اور زور سے پکڑتے اور ملتے ہیں۔

س۔ کچھ افراد کو درد محسوس ہی نہیں ہوتا۔

ق۔ کچھ بچوں کو گرمی اور سردی کا احساس نہیں ہوتا۔یعنی ان کا جسم درجہ حرارت کو محسوس نہیں کر پاتا۔

ل۔ کچھ افراد خود کو نقصان پہنچاتے ہیں، یعنی جسمانی اذیت دے سکتے ہیں۔مثلاً کاٹ لینا، جلا لینا، اپنے سر کو دیوار پر مارنا وغیرہ۔

م۔ کچھ بچے اپنے جسم پر وزنی اشیاء کا رکھا جانا پسند کرتے ہیں اور اس سے لطف اندوز ہوتے ہیں۔

(v) <u>چکھنے کی حس سے متعلق مسائل:</u>

الف۔ کچھ بچے بہت ہی چٹ پٹا کھانا پسند کرتے ہیں۔

ب۔ کچھ بچے سب کچھ کھا جاتے ہیں۔مثلاً مٹی، گھاس، یا کوئی بھی دوسری چیز۔

ج۔ کچھ بچے صرف مخصوص قسم اور ذائقہ کا کھانا پسند کرتے ہیں۔

(vi) <u>سونگھنے کی حس سے متعلق مسائل:</u>

الف۔ کچھ بچوں کے سونگھنے کی حس بہت کمزور ہوتی ہے، اور انہیں شدید ترین بدبو بھی محسوس نہیں ہوتی

ب۔ کچھ بچے، جن کی سونگھنے کی حس کمزور ہو، وہ بعض اوقات تیز بدبودار اشیاء کو چاٹ لیتے ہیں مثلاً پاخانہ یا کسی بدبودار چیز کو چاٹنا۔

ج۔ کچھ بچوں کی سونگھنے کی حس بہت تیز ہوتی ہے، اور وہ باتھ روم جانا پسند نہیں کرتے۔

د۔ کچھ بچے خوشبودار اشیاء، مثلاً عطر، شیمپو وغیرہ پسند نہیں کرتے۔

حواس سے متعلق بہت سے مسائل اوپر درج کئے گئے ہیں۔ مگر ایک بات ذہن میں رکھنی چاہیے کہ آٹیزم میں مبتلا تمام افراد کو، اوپر بیان کئے گئے تمام مسائل نہیں ہوتے۔ کچھ بچوں کو ان میں سے چند مسائل درپیش ہوتے ہیں۔ جبکہ بعض کو ان میں ایک بھی مسئلہ درپیش نہیں ہوتا۔

<u>حواس سے متعلق مسائل حل کرنے کے لئے چند اہم تجاویز:</u>

☆ <u>حسی لحاظ سے آرام دہ ماحول کی فراہمی:</u>

بچے کی ضروریات کے مطابق آرام دہ اور پرسکون ماحول مہیا کرنے کی کوشش کریں۔ جس میں بچے کے حواس سے متعلق، مسائل کو ذہن میں رکھا جائے، تاکہ بچے کو ذہنی دباؤ اور پریشانی سے بچایا جاسکے۔

☆ <u>بچے کو پیشگی آگاہ کریں:</u>

یعنی اگر آپ بچے کو بازار ساتھ لے کر جارہے ہیں، تو اسے پہلے ہی سمجھائیں کہ ہم بازار جا رہے ہیں۔ وہاں شوروغل زیادہ ہوگا۔ تاکہ بچہ خود کو شور کے لئے تیار کرلے۔

(i) <u>جسمانی توازن اور جسمانی آگاہی سے متعلق مسائل پر قابو پانے کے طریقے:</u>

الف۔ بچوں کو ایسے کھیلوں اور سرگرمیوں میں حصہ دلوائیں، جس سے اس کے جسمانی توازن اور

جسمانی آگاہی کے نظام میں بہتری پیدا ہو۔ مثلاً بچے کی حوصلہ افزائی کریں کہ وہ مختلف طرح کے جھولے جھولے (آگے پیچھے ہونے والے، لٹکنے والے، اور مختلف طرح کے جھولے)۔ اسی طرح پارک میں آگے پیچھے ہلنے والے گھوڑے اور دوسرے جھولوں پر بٹھائیں۔

ب۔ بہتر جسمانی نشوونما کے فروغ کے لئے بچے کی حوصلہ افزائی کریں، کہ وہ مصوری، ڈرائنگ، پینٹنگ، پزل کے ٹکڑے جوڑنے کی سرگرمی، دھاگے میں اشیاء پرونے کی سرگرمی، وغیرہ میں حصہ لے۔ یا ایسی سرگرمیاں جس میں باریکی سے کام کرنا ہو اور جسم کے اعضاء میں ربط پیدا ہو۔

ج۔ کمرے میں فرنیچر کی ایسی ترتیب لگائیں، کہ بچہ آسانی سے کمرے میں گھوم پھر سکے۔ بہت زیادہ فرنیچر، بچے کے لئے کمرے میں چلنا پھرنا دشوار کر دیتا ہے۔

د۔ بچے کو ذاتی جگہ کے تصور (یعنی گفتگو کے دوران دوسرے شخص سے کتنی دور کھڑا ہونا چاہیے) سکھانے کے لئے مختلف طریقے استعمال کریں۔ جیسا کہ ہاتھ کی لمبائی کا اصول۔ یعنی جو بچے دوسرے لوگوں کے بہت نزدیک کھڑے ہو کر بات کرتے ہیں، کہ دوسرا شخص کوفت محسوس کرنے لگے۔ ایسے بچوں کے لئے ایک اصول بنائیں کہ وہ جب بھی کسی سے بات چیت کرنا چاہیں، تو پہلے اپنے بازو کو سامنے کی طرف کھول کر دیکھیں، کہ وہ دوسرے شخص سے کم از کم ایک بازو کے فاصلے پر دور کھڑے ہیں کہ نہیں۔ اس طرح وہ دوسرے شخص سے مناسب فاصلے پر کھڑے ہو کر گفتگو کرنا سیکھ جائیں گے۔

(ii) سننے کی حس یا آواز سے متعلق مسائل پر قابو پانے کے طریقے:

الف۔ اگر آپ بچے کو کسی شور وغل والی جگہ پر لے جا رہے ہوں، تو بچے کو پہلے ہی بتا دیں۔ تا کہ وہ ذہنی طور پر تیار ہو جائے۔

ب۔ اگر بچہ آواز کے متعلق حساس ہے، یا شور وغل سے گھبراتا ہے، تو گھر میں ایک ایسا کونہ بنائیں، جہاں جا کر بچہ کچھ دیر کے لئے پر سکون ہو سکے۔ یہ کونہ، باورچی خانہ اور ٹی وی لاؤنج سے دور ہونا چاہیے۔ کیونکہ ایسی جگہوں پر عموماً گھر والوں کی آمد ورفت اور شور وغل زیادہ ہوتا ہے۔ بیڈ روم یا کسی کمرے کا کوئی کونہ مخصوص کر دیں، جہاں جا کر بچہ کچھ دیر کے لئے آرام کر سکے، اور شور وغل دور کر کے پر سکون ہو جائے۔

ج۔ جو بچے شور وغل سے گھبراتے ہوں، ان کے لئے ذاتی سٹیریو (یعنی ہیڈ فون) کا بھی انتظام کیا جا سکتا ہے۔ تا کہ بیرونی آوازیں انہیں تنگ نہ کریں۔ اور وہ اپنی پسند کے گانے سنتے رہیں۔

د۔ کان میں لگانے والے پلگ بھی استعمال کئے جا سکتے ہیں۔

(iii) دیکھنے کی حس سے متعلق مسائل پر قابو پانے کے طریقے:

الف۔ اگر بچہ تیز روشنی سے گھبراتا ہو، تو مدہم روشنی والے بلب یا گہرے رنگوں والے بلب لگائے جا سکتے ہیں۔

ب۔ کھڑکیوں پر گہرے رنگوں کے پردے لگانے سے بھی باہر کی تیز روشنی سے بچا جا سکتا ہے۔

ج۔ گھر سے باہر جاتے وقت چشمہ استعمال کیا جا سکتا ہے۔

(iv) چھونے کی حس سے متعلق مسائل پر قابو پانے کے طریقے:

الف۔ جو بچے یہ پسند نہیں کرتے کہ کوئی انہیں ہاتھ لگائے۔ اگر آپ ایسے بچے کو چھونے لگیں، یا گلے لگانا چاہیں، تو اسے پہلے بتائیں کہ آپ ایسا کرنا چاہتے ہیں۔ تاکہ وہ اس کے لئے ذہنی طور پر تیار ہو جائے۔

ب۔ بچہ جن کپڑوں میں آرام دہ محسوس کرے، اسے وہی کپڑے پہننے دیں۔

ج۔ بتدریج مختلف قسم کے کپڑے، یعنی مختلف ساخت و ڈیزائن کے کپڑے متعارف کرائیں۔

د۔ جو بچے وزنی اشیاء اپنے اوپر رکھنا پسند کرتے ہیں، ان کے لئے سردیوں میں رضائی یا وزنی کمبل رات کے وقت استعمال کیا جا سکتا ہے۔

ر۔ بچے کو پانی، ریت، مٹی اور اسی طرح کی دوسرا اشیاء سے کھیلنے کے مواقع فراہم کریں۔

(v) چکھنے کی حس سے متعلق مسائل پر قابو پانے کے طریقے:

الف۔ مختلف اقسام کے کھانے آہستہ آہستہ متعارف کرائیں۔

ب۔ کھانے کی ساخت بدل دیں۔ مثلاً آلو کچل دیں، وغیرہ۔

ج۔ بچے کو ایسی سرگرمیاں کرائیں، جس میں منہ استعمال ہو۔ مثلاً چیونگم یا کوئی اور چیز چبانا، منہ سے کھلونے میں ہوا بھرنا، وغیرہ۔

(vi) سونگھنے کی حس سے متعلق مسائل پر قابو پانے کے طریقے:

الف۔ جن بچوں کے سونگھنے کی حس کمزور ہو اور وہ بدبودار اشیاء چاٹ جاتے ہوں۔ یا بدبودار اشیاء جیسے پاخانہ وغیرہ، سونگھنا پسند کرتے ہوں۔ ان کے لئے تیز خوشبو والی مصنوعات استعمال

کریں۔تا کہ ان کی توجہ بد بودار اشیاء سے ہٹائی جا سکے۔

ب۔ جن بچوں کے سونگھنے کی حس تیز ہو۔یعنی وہ پرفیوم،شیمپو، وغیرہ کی تیز مہک برادشت نہ کر سکتے ہوں،ان کے لئے خوشبو سے پاک اشیاء استعمال کریں۔

<u>چند اہم باتیں:</u>

اوپر دی گئی تجاویز کو تمام بچوں پر استعمال نہ کریں۔اس لئے کہ آٹیزم ہر بچے پر مختلف انداز میں اثر انداز ہوتا ہے اور ہر بچے کی علامات دوسرے بچے سے مختلف ہوتی ہیں۔اس لیے آپ کے بچے کو جو خاص مشکل درپیش ہو،صرف اسی سے متعلقہ تجویز پر عمل کرنا بچے کو فائدہ دے سکتا ہے۔

ایک اور اہم بات یہ ہے کہ بچے کے حواس سے متعلق دشواریوں پر قابو پانے میں مدد تو ضرور دیں۔اور بچے کو ایسا آرام دہ ماحول فراہم کریں کہ جن چیزوں سے اسے تکلیف اور گھبراہٹ ہوتی ہے، وہ بچے کے کمرے یا اردگرد کے ماحول سے ختم کر دی جائیں۔تا کہ اسے ذہنی اضطراب سے بچایا جا سکے۔لیکن مکمل طور پر ان اشیاء کو بچے کی زندگی سے نکال دینے سے، بچہ اور زیادہ حساس بن سکتا ہے،اور اس کی حواس سے متعلق مشکلات مزید پیچیدہ ہو سکتی ہیں۔اس لئے بچے کو آہستہ آہستہ ایسی اشیاء سے متعارف کراتے رہیں،تا کہ اس کی حساسیت کو کم کیا جا سکے۔

5۔ <u>تبدیلی پر مزاحمت اور معمول سے محبت :</u>

آٹیزم میں مبتلا افراد کو اپنے ارگرد کے ماحول کو سمجھنے میں بہت مشکل پیش آتی ہے۔ان کے لئے دنیا ایک عجیب وغریب جگہ ہے۔جہاں ہر وقت کچھ نہ کچھ نیا اور عجیب واقعہ رونما ہوتا رہتا ہے۔جہاں کوئی بھی چیز ایک جیسی نہیں رہتی۔ان کیلئے دنیا ایک غیر متوقع اور پریشان کن، الجھا دینے والی جگہ ہے

تیزی سے بدلتا ہوا ماحول ان میں خوف اور بے چینی پیدا کر دیتا ہے۔ اس خوف اور اضطراب پر قابو پانے کے لئے آٹیزم میں مبتلا افراد اکثر:

i) ترتیب اور معمولات کو ترجیح دیتے ہیں۔

ii) ہمیشہ ایک ہی راستہ پر سفر کرنا پسند کرتے ہیں۔ یعنی سکول جانے کے لئے ہمیشہ ایک ہی راستہ استعمال کیا جائے۔ روزانہ مختلف راستوں سے سکول جانے پر رونا اور چیخنا چلانا شروع کر دیتے ہیں۔ اسی طرح پارک، بازار، McDonalds، وغیرہ جانے کے لئے جو راستہ ایک بار استعمال کیا جائے، پھر وہ ہمیشہ اسی راستے سے جانا پسند کرتے ہیں اور تبدیلی پر گھبرا جاتے ہیں۔

iii) تبدیلی کو ناپسند کرتے ہیں (مثلاً گھر یا سکول کی تبدیلی، فرنیچر کی تبدیلی، کسی چیز کو اس کی جگہ سے ہٹانا یا ہلانا، کھلونے یا کسی اور چیز کی تبدیلی، وغیرہ)۔

iv) ہمیشہ ایک ہی طرح کا کھانا پسند کرنا اور ہمیشہ ایک ہی طرح کے کپڑے پہننا۔

<u>تبدیلی اور معمولات سے متعلق چند اہم تجاویز:</u>

i) تبدیلی آہستہ آہستہ متعارف کرائیں۔

ii) کسی بھی چیز کے تبدیل کرنے سے پہلے بچے کو اس تبدیلی کے بارے میں آگاہ کریں۔

iii) تبدیلی کی وجہ بھی بچے کو بتائی جائے، یعنی کس وجہ سے یہ تبدیلی لائی جا رہی ہے۔

iv) چونکہ بچہ معمولات اور ترتیب کو پسند کرتا ہے، اس کی اس صلاحیت سے فائدہ اٹھائیں اور اس کے روزانہ کے کاموں کا ٹائم ٹیبل بنا دیں۔ اس طرح وہ خوشی خوشی اپنے معمول کے مطابق

کام کرے گا۔ پورے دن کا اور ہفتہ وار شیڈول بنانے سے، بچے ذہنی اضطراب کے بغیر بخوبی پڑھائی اور دیگر کام کر سکتے ہیں۔

6- خاص دلچسپیاں:

آٹیزم میں مبتلا بعض افراد شدید نوعیت کی خصوصی دلچسپیاں رکھتے ہیں۔ اگر انہیں ان کی مخصوص دلچسپی یا پسندیدہ سرگرمی سے روکا جائے، تاکہ وہ کوئی اور کام کریں (یعنی پڑھائی، سونا، نہانا، سکول جانا، وغیرہ)، تو وہ شدید اضطراب کا شکار ہو سکتے ہیں اور شدید ردعمل کا اظہار بھی کر سکتے ہیں، جیسے رونا پیٹنا، چیخنا چلانا، شور مچانا، دوسروں کو مارنا وغیرہ۔ یہ دلچسپیاں مندرجہ ذیل نوعیت کی ہو سکتی ہیں۔

i) بعض بچے کار، ٹرین، کمپیوٹر، کسی کھلونے، کسی مخصوص ٹی وی پروگرام یا کسی جانور، وغیرہ میں شدید دلچسپی رکھتے ہیں۔

ii) بعض افراد اپنی پسند کے موضوع پر یا اپنی دلچسپی سے متعلق گھنٹوں بات کرتے رہتے ہیں۔

iii) بعض افراد یہ اندازہ نہیں لگا سکتے کہ دوسرے لوگ ان کی باتیں سن سن کر تھک گئے ہیں، اور یہ کہ دوسرے لوگوں کو ان کی پسند کی چیز میں شدید حد تک دلچسپی نہیں ہے۔

شدید نوعیت کی خصوصی دلچسپیوں سے متعلق چند اہم تجاویز:

i) یاد رہے کہ بچے اپنی خصوصی دلچسپیوں کے معاملے میں بہت حساس ہوتے ہیں۔ اس لئے انہیں اپنی پسند کی سرگرمیوں یا پسندیدہ کھلونے سے کھیلنے کے لئے کچھ وقت ضرور دیں۔

ii) بچے کی پسندیدہ چیز کو انعام کے طور پر بھی استعمال کیا جا سکتا ہے۔ مثلاً اگر آپ بچے سے کوئی خاص کام کروانا چاہتے ہیں۔ جیسا کہ دانت صاف کرنا تو اس سے کہیں کہ: "پہلے دانتوں میں برش کرو، پھر تمہیں تمہاری کار ملے گی"۔

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نامناسب حرکات یا غلط رویے کی روک تھام کیلئے تجاویز

آٹیزم میں مبتلا چند بچوں کو رویے سے متعلق مسائل بھی درپیش ہو سکتے ہیں۔ بچوں کے نامناسب یا غلط رویے کے متعلق پوچھے جانے والے چند عام سوالات مندرجہ ذیل ہیں۔

سوال نمبر 1: کیا آٹیزم میں مبتلا بچے کو بدتمیزی، نامناسب حرکات یا غلط رویے سے روکنا چاہیئے؟

جواب: جی ہاں! بچے کو نامناسب رویے اور حرکات سے روکنا بے حد ضروری ہے۔ بعض والدین کا یہ خیال ہے کہ بچے کو غلط حرکات اور نامناسب عادات پر روکنے ٹوکنے سے بچے کی شخصیت دب جاتی ہے اور اس میں اعتماد پیدا نہیں ہوتا۔ جب کہ حقیقت اس کے بالکل برعکس ہے۔ اگر بچے کو اس کی نامناسب حرکات اور غلط رویے پر نہ روکا جائے، تو اس میں بہت سی غلط عادات پختہ ہو جاتی ہیں۔ جو اس کی شخصیت پر برے اثرات مرتب کرتی ہیں۔ اس کے علاوہ بعض والدین کا یہ بھی خیال ہے کہ آٹیزم میں مبتلا بچے کی سمجھ بوجھ چونکہ محدود ہوتی ہے، اس لیے اسے نامناسب حرکات سے روکنے کا کوئی فائدہ نہیں، جب کہ یہ خیال بھی بالکل غلط ہے بچے کو جس طرح کی تربیت کی جائے، اس کی شخصیت اسی طرح ڈھالی جا سکتی ہے۔ آٹیزم میں مبتلا بچے کو بھی ہرگز یہ اجازت نہ دیں کہ وہ دوسرے بچوں کو مارے پیٹے، گھر میں کپڑے اتار کر بھاگتا پھرے، مہمانوں پر چھلانگیں لگائے، جگہ جگہ فرش پر تھوکتا پھرے، کھانے پینے کی اشیاء یا کھلونے سارے گھر میں بکھیر دے، وغیرہ۔

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سوال نمبر 2: کیا آٹیزم میں مبتلا بچے کو غلط رویے یا نامناسب حرکات پر مارنا پیٹنا چاہئے؟

جواب: نہیں! بچے کو مارنے پیٹنے سے اس نامناسب رویے یا غلط حرکت کی اصل وجہ کو ختم نہیں کیا جا سکتا۔ ممکن ہے کہ بچہ کسی دوسرے وقت میں وہی حرکت دوبارہ کرے، یا پھر کسی اور قسم کی غلط حرکت کرنے لگے، جو پہلی حرکت سے بھی زیادہ بری ہو۔ اس لیے مار پیٹ سے مکمل طور پر گریز کریں اور بچے کو ہرگز نہ ماریں۔

ماہرین کا خیال ہے کہ انسان کی ہر حرکت اور رویے کے پیچھے کوئی نہ کوئی وجہ ضرور ہوتی ہے۔ اگر آٹیزم میں مبتلا بچہ کوئی غلط حرکت کرتا ہے، تو اس کا مطلب یہ ہوا کہ بچے کو کوئی مسئلہ درپیش ہے، جسے وہ حل نہیں کر پا رہا ہے۔ مثلاً ممکن ہے کہ وہ اپنی ضروریات کو ٹھیک طرح سے بتا نہ پائے، یا پھر اسے مہمانوں کے ساتھ بیٹھنے میں گھبراہٹ ہو رہی ہو، یا شور وغل سے گھبرا جائے، یا کسی اور وجہ سے ذہنی دباؤ کا شکار ہو۔ آٹیزم میں مبتلا بچے اپنے اردگرد کی دنیا کو سمجھنے میں دشواری محسوس کرتے ہیں۔ بعض اوقات انہیں سمجھ ہی نہیں آتی کہ لوگ ان سے کیا چاہتے ہیں۔ اس لئے ان کے غلط و نامناسب رویے کی وجہ ناسمجھی اور غلط فہمی ہو سکتی ہے۔

غلط رویے اور بری عادات کو ختم کرنے کا بہترین طریقہ یہ ہے کہ اس غلط رویے کی اصل وجہ کو تلاش کیا جائے اور بچے کا وہ مسئلہ حل کر دیا جائے، تو غلط رویہ خود بخود ختم ہو جائے گا۔

سوال نمبر 3: آٹیزم میں مبتلا بچے کے نامناسب رویے اور غلط حرکات کی کیا وجوہات ہیں؟

جواب: بچے کے غلط و نامناسب رویے کی مندرجہ ذیل وجوہات ہو سکتی ہیں:

1- ذہنی اضطراب و پریشانی:

بچے کے غلط رویے کی ایک ممکنہ وجہ ذہنی دباؤ اور پریشانی ہے۔ اگر بچہ کسی وجہ سے پریشان ہو یا گھبراہٹ کا شکار ہو، تو اس کا اثر اس کے رویے پر پڑتا ہے۔

2- تبدیلی:

بچے کے غلط رویے اور نامناسب حرکات کی ایک وجہ تبدیلی بھی ہوسکتی ہے۔ مثلاً گھر کا فرنیچر تبدیل کرنا، بچے کا کمرہ بدل دینا، گھر کی تبدیلی، سکول کی تبدیلی، کلاس کی تبدیلی، ٹیچر کا بدل جانا، وغیرہ۔ اس کے علاوہ ایک سرگرمی کو ختم کر کے دوسری سرگرمی شروع کرنا، یا ایک کام چھوڑ کر دوسرا کام کرنا، یا پھر چھٹیاں گھر گزارنے کے بعد سکول جانا، وغیرہ۔ یعنی بچے کے روزمرہ معمولات میں تبدیلی بے چینی اور ذہنی دباؤ پیدا کرسکتی ہے۔

3- دوسرے لوگوں کے رویے کے بارے میں غلط فہمی:

جیسا کہ آٹیزم میں مبتلا بچے دوسروں کے جذبات و احساسات اور رویوں کو ٹھیک طرح سے سمجھ نہیں پاتے۔ اس لئے ممکن ہے کہ وہ کسی شخص کی کسی خاص بات یا رویے کو غلط سمجھیں۔ اور اس غلط فہمی اور ناسمجھی کی وجہ سے نامناسب رویے یا حرکات کا مظاہرہ کریں۔

4- لوگوں میں اٹھنے بیٹھنے اور میل جول کے طریقوں سے ناواقفیت:

آٹیزم میں مبتلا افراد کی سوچنے سمجھنے اور (خود بخود) دوسروں کو دیکھ کر سیکھنے کی صلاحیتیں بہت محدود ہوتی ہیں۔ بعض اوقات انہیں چھوٹی چھوٹی باتیں سکھانی پڑتی ہیں، جو دوسرے بچے از خود سیکھ لیتے ہیں۔ جیسا کہ مہمانوں کے ساتھ کس طرح پیش آنا چاہئے، بازار میں کون سی حرکتیں نامناسب سمجھی جاتیں ہیں، وغیرہ۔

5- اپنی ضروریات کا اظہار کرنے میں ناکامی:

آٹیزم میں مبتلا بچے چونکہ بات چیت اور ملنے جلنے کے آداب سے واقف نہیں ہوتے، اس لئے بعض اوقات وہ اپنی ضروریات پوری کرنے کے لئے آسان طریقہ استعمال کرتے ہیں، جو دوسرے لوگوں کو نامناسب اور غلط محسوس ہوتا ہے۔ مثال کے طور پر ممکن ہے کہ آٹیزم میں مبتلا بچے کو یہ معلوم ہی نہ ہو کہ بسکٹ یا کھلونا دوسرے بچے سے کیسے مانگنا چاہئے۔ ایسے میں ممکن ہے کہ وہ اسے دوسرے بچے کے ہاتھ سے چھین لے۔ اسی طرح اگر بچہ پارک میں جانا چاہے، لیکن والدین سے فرمائش کرنے کا طریقہ سمجھ میں نہ آئے، تو ممکن ہے کہ وہ رونے لگے، چیخنے چلانے لگے، چیزیں ادھر ادھر پھینکنے لگے یا کسی دوسرے بچے کو مارنے لگے۔

6- غیر یقینی صورتحال کا خوف:

آٹیزم میں مبتلا بچے غیر متوقع صورتحال، اچانک تبدیلی، ناواقف راستے، اچانک کہیں آنا جانا، اچانک کسی کا آجانا، وغیرہ سے گھبراہٹ کا شکار ہو سکتے ہیں۔ بدلتی ہوئی صورتحال ان بچوں میں پریشانی اور خوف پیدا کر دیتی ہے، اور ان کے غلط رویے کی ایک وجہ بن سکتی ہے۔

7- غیر آرام دہ ماحول:

جیسا کہ آٹیزم میں مبتلا بچوں کو معاشرتی میل جول، گفتگو، سوچنے سمجھنے کی صلاحیت اور حواس سے متعلق مختلف قسم کے مسائل کا سامنا ہوتا ہے۔ اس لئے وہ ایسے ماحول میں خود کو غیر آرام دہ محسوس کرتے ہیں، جو انکی مشکلات سے متعلق ہو۔ مثلاً پرہجوم مقامات، شادی بیاہ و دیگر تقریبات میں بچے بے سکون ہو سکتے ہیں۔ نیز ایسی جگہیں جہاں تیز لائٹیں، اونچی آوازیں،

شوروغل، بہت تیز خوشبو ہو، ایسی جگہیں بھی آٹیزم میں مبتلا بچوں کے لئے تکلیف و بے سکونی کا سبب بن سکتی ہے۔

-8 طویل کام کرنے میں ناکامی:

آٹیزم میں مبتلا بچے ایسے کام کرنے میں دشواری محسوس کرتے ہیں، جو لمبے عرصے کا ہو۔ یہ بچے کسی بھی کام پر بہت تھوڑی دیر توجہ برقرار رکھ سکتے ہیں۔ اگر کوئی کام لمبا ہو، اور اسے کرنے میں کافی وقت لگے، تو بچے اکتاہٹ کا شکار ہو کر نامناسب رویے کا مظاہرہ کر سکتے ہیں۔

سوال نمبر 4: آٹیزم میں مبتلا بچے کے غلط و نامناسب رویے کو کس طرح روکا جا سکتا ہے؟

جواب: مندرجہ ذیل تجاویز بچے کے غلط و نامناسب رویے کو روکنے میں مددگار ثابت ہو سکتی ہیں:

-1 بچے کے رویے کا جائزہ لیں:

اگر بچہ کسی غلط رویے یا نامناسب حرکت کا اظہار کرے، جیسا کہ کسی دوسرے بچے کو مارے پیٹے، چیخے چلائے، چیزیں ادھر اُدھر پھینکے وغیرہ تو اس کا جائزہ لیں کہ وہ کب غلط حرکت کرتا ہے۔ اس بات پر غور کریں کہ بچہ کب اور کیوں پریشان ہوتا ہے۔ اور اس کے نامناسب رویے کے پیچھے کیا وجہ ہو سکتی ہے۔ نامناسب رویے کی اصل وجہ تلاش کریں اور اس بنیادی وجہ سے نمٹنے کی کوشش کریں، تاکہ مسئلہ دوبارہ پیدا نہ ہو۔

-2 آٹیزم کے حوالے سے آرام دہ ماحول کی فراہمی:

اونچی آوازیں، شوروغل، بہت تیز روشنیاں، خوشبو اور اسی طرح کی دوسری بہت سی چیزیں

آٹیزم میں مبتلا بچوں میں بے چینی اور گھبراہٹ کا سبب بن سکتی ہیں ۔ یہ بے چینی اور اضطراب بچے کو غلط رویے اور نا مناسب حرکات پر ابھار سکتا ہے۔اس لئے بچوں کے اردگرد کا ماحول آرام دہ ہونا چاہیے،اور ایسی تمام اشیاء سے پاک ہونا چاہیے جو بچے میں اضطراب پیدا کریں۔

-3 <u>بچے کو تبدیلی کے لئے تیار کریں:</u>

بچے کو پہلے ہی بتا دیں کہ آپ فرنیچر، گھر، سکول، کلاس، یا کچھ اور تبدیل کر رہے ہیں۔سماجی کہانیاں (Social Stories)،شیڈول، ٹائم ٹیبل وغیر،اس ضمن میں فائدہ مند ثابت ہو سکتے ہیں۔

-4 <u>منظّم شیڈول استعمال کریں:</u>

بچے کی دن بھر کی تمام اہم سرگرمیوں کی منظّم فہرست بنائیں۔اس طرح بچے کو یہ بھی معلوم ہو جائے گا کہ ایک دن میں اسے کیا کیا کام کرنے ہیں، اور یہ کہ والدین کی اس سے کیا توقعات وابستہ ہیں۔مزید یہ کہ اسے یہ بھی معلوم ہوگا کہ ایک کام کے بعد، دوسرا کام کونسا ہے۔اس طرح غیر متوقع صورتحال سے پیدا ہونے والے اضطراب سے بچا جا سکتا ہے۔

-5 <u>اپنا انداز گفتگو تبدیل کریں:</u>

گفتگو اور بات چیت سے متعلقہ مسائل کے ضمن میں اوپر دی گئی تجاویز بھی بہت سے غلط و نا مناسب رویوں کی روک تھام میں اہم کردار ادا کر سکتی ہیں (دیکھئے صفحہ نمبر 5)

-6 <u>طویل کام کو چھوٹے چھوٹے حصوں میں تقسیم کرنا:</u>

مثال کے طور پر بچے کو اگر پتلون پہننا سکھانا ہو، تو اس مہارت کو اسے تین حصوں میں تقسیم کر

کے سکھائیں۔ جیسا کہ پتلون میں ٹانگیں ڈالنا، پتلون کا بٹن بند کرنا اور تیسرا کام پتلون کی زپ بند کرنا ہے۔ پہلے بچے کو ان میں سے ایک کام سکھائیں۔ جب ایک میں مہارت ہو جائے، تو پھر دوسرا، پھر تیسرا سکھائیں۔ اسی طرح ہر بڑے کام کو چھوٹے چھوٹے حصوں میں تقسیم کر کے، پھر ہر چھوٹا کام ایک ایک کر کے سکھائیں۔

-7 <u>بچے کی حوصلہ افزائی کریں:</u>

بچے کے لئے کچھ سیکھنا یا اپنی عادت کو بدلنا بہت دشوار کام ہوتا ہے۔ اگر وہ کوئی بھی اچھا کام کرے، تو اس کی حوصلہ افزائی کریں اور اس کی کوشش کی تعریف کریں۔ مزید یہ کہ بچے کو اس بات کا بھی احساس دلائیں کہ اس کے اندر کاموں کو کرنے کی اہلیت موجود ہے۔ اس لئے وہ ہمت نہ ہارے اور ہر کام سیکھ لینے کا جذبہ برقرار رکھے۔

-8 <u>انعامات:</u>

بچے کو اچھے رویے اور عمل پر انعام دینا چاہیے۔ ابتداء میں ممکن ہے کہ بچہ معاشرتی تعریف کو نہ سمجھ سکے۔ جیسا کہ ''شاباش'' وغیرہ، اور اسے انعام تصور نہ کرے۔ اس لئے شروع میں بچے کا پسندیدہ کھلونا، پسندیدہ کھانا یا پسندیدہ کھیل انعام کے طور پر استعمال کیا جاسکتا ہے لیکن جب بچے کو یہ انعام (کھلونا، کھانے کی چیز وغیرہ) دیا جائے، تو ساتھ میں سماجی تعریف متعارف کروائیں۔ یعنی بچے کے اچھے کام سے خوش ہو کر اسے کھانے کی چیز دیتے ہوئے، ساتھ میں یہ بھی کہیں کہ ''شاباش''، ''بہت اچھا کام کیا''، یا ''تم بہت اچھے بچے ہو''، وغیرہ۔

9- صبر سے کام لیں:

بچے کے غلط اور نا مناسب رویے کو تبدیل کرنے میں کچھ وقت لگ سکتا ہے۔ اگر بچے کے رویے میں فوراً کوئی مثبت تبدیلی ظاہر نہ ہو، تو امید ہرگز نہ چھوڑیں۔ نیز جو حکمت عملی اختیار کی ہے، اسے جاری رکھیں۔

10- ایک ہی حکمت عملی جاری رکھیں:

بچے کے غلط اور نا مناسب رویے کو روکنے کے لئے جو حکمت عملی اختیار کریں، وہ کچھ عرصے تک جاری رکھیں۔ (کوئی بھی حکمت عملی یا طریقہ کار جادو کی چھڑی کی طرح کام نہیں کرتے کہ آپ اسے استعمال کریں اور فوراً ہی بچے کا غلط رویہ ٹھیک ہو جائے)۔ عادت کی تبدیلی میں وقت لگتا ہے۔ اس لئے دل برداشتہ ہو کر ہر روز حکمت عملی تبدیل نہ کریں۔

سوال نمبر 5: آٹیزم میں مبتلا بچے کے بہن بھائی بعض اوقات اسے پسند نہیں کرتے اور اپنے خاندان کا حصہ نہیں سمجھتے۔ اس مسئلے کو کیسے حل کیا جائے کہ بچے کے بہن بھائی اسے اپنے خاندان کا حصہ قبول کر لیں؟

جواب: چونکہ آٹیزم میں مبتلا بچے کو عام بچوں کی نسبت زیادہ دیکھ بھال، وقت اور توجہ کی ضرورت ہوتی ہے۔ والدین کی آٹیزم میں مبتلا بچے کے لئے زیادہ توجہ، اس کے دوسرے بہن بھائیوں میں اضطراب و پریشانی اور غم و غصے کے جذبات کو پیدا کر سکتی ہے۔ اور ممکن ہے کہ وہ ایسا محسوس کریں کہ والدین انہیں نظر انداز کر دیتے ہیں۔

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اس مسلئے کو حل کیا جا سکتا ہے، اگر:

الف۔ والدین تمام بچوں کے لئے ایک متوازن اور مثبت نقطہ نظر رکھیں۔

ب۔ والدین تمام بچوں کے ساتھ ایک جیسی محبت اور اپنائیت سے پیش آئیں۔

ج۔ والدین آٹیزم میں مبتلا بچے کے بہن بھائیوں کو اس بچے کی تعلیم و تربیب اور دیکھ بھال میں شامل کریں۔

د۔ والدین تمام بچوں کے ساتھ ایک جیسا سلوک کریں۔

ر۔ والدین بچے کے بہن بھائیوں کو یہ احساس دلائیں کہ وہ اہم ہیں۔ اور اپنے آٹیزم میں مبتلا بہن یا بھائی کی دیکھ بھال میں ان کا کردار بہت اہمیت کا حامل ہے۔

س۔ آٹیزم میں مبتلا بچے کے بہن بھائی جب اس بچے کی مدد کریں یا دیکھ بھال کریں، تو ان کی تعریف کریں اور انکی مدد کو سراہیں۔

آٹیزم میں مبتلا بچے کے لئے اس کے بہن بھائی ایک بہت بڑی نعمت ثابت ہو سکتے ہیں۔ بہن بھائیوں کی وجہ سے بچہ لوگوں کو اپنے ارد گرد برداشت کرنے کا عادی ہو جاتا ہے۔ اسی طرح گفتگو و بات چیت، لوگوں سے میل جول اور بہت سی چھوٹی چھوٹی عام باتیں بھی بچہ اپنے بہن بھائیوں سے سیکھتا ہے۔ بچے کے بہن بھائی اس کے لئے ایک نمونے کے طور پر کام کر سکتے ہیں۔ اور بچہ ان کو دیکھ کر بہت سی باتیں سیکھ سکتا ہے۔ جیسا کہ اپنی باری کا انتظار کرنا، مل جل کر کھیلنا، دوست بنانا، لوگوں سے ملنا جلنا وغیرہ۔

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آٹیزم میں مبتلا بچوں کے علاج کے لئے استعمال ہونے والی

حکمت عملیوں کا مختصر تعارف :

بہت سے ایسے طریقے اور علاج ہیں، جو آٹیزم سے متعلقہ مسائل کی ایک بڑی تعداد کو کم کرنے میں مدد دیتے ہیں۔ آٹیزم میں مبتلا ہر بچے کی علامات، دوسرے بچے سے مختلف ہوتی ہیں۔ اسی لئے تمام بچوں کے لئے ایک ہی علاج یا طریقہ تجویز نہیں کیا جا سکتا۔ ہر علاج، تھراپی، یا طریقہ تمام لوگوں کے لئے فائدہ مند نہیں ہوسکتا۔ کچھ لوگوں کو ایک تھراپی یا علاج سے فائدہ ہوتا ہے۔ جبکہ بعض دوسرے لوگوں کو اس سے کوئی فائدہ نہیں ہوتا۔ اہم بات یہ ہے کہ علاج یا طریقہ کار کا انتخاب کرتے وقت، بچے کی مشکلات و مسائل کو ذہن میں رکھیں اور وہ علاج یا طریقہ کار منتخب کریں، جو بچے کی ضروریات کے مطابق ہو۔ مختلف قسم کے علاج و طریقہ کار کا مختصر تعارف اس حصے میں شامل کیا گیا ہے۔ مگر یہ تعارف نہایت مختصر اور معلومات کی غرض سے ہے۔ تفصیلی طریقہ کار کتب یا انٹرنیٹ پر دیکھا جا سکتا ہے۔ جن میں سے چند اہم کی فہرست اس کتابچے کے آخر میں موجود ہے۔

1- غذائی علاج و طریقہ کار (Dietary Intervention):

آٹیزم میں مبتلا بعض بچے کھانے کی بعض اشیا کو ہضم نہیں کر پاتے۔ کچھ کھانے ان کے رویے، مزاج، سیکھنے کے عمل اور نظام انہضام پر اثر انداز ہو سکتے ہیں۔ گلوٹن (Gluten) اور کیسین (Casein) کے بارے میں یہ خیال کیا جاتا ہے کہ یہ دونوں بچے پر اثر انداز ہو سکتے ہیں۔ گلوٹن ایک پروٹین (نشاستہ) ہے، جو گندم، جو، اور دیگر اناج میں پایا جاتا ہے۔ کیسین بھی ایک پروٹین ہے، جو دودھ اور دودھ سے بنی ہوئی اشیاء مثلاً دہی، مکھن، ملائی، پنیر وغیرہ میں پائی جاتی ہے۔ آٹیزم میں مبتلا بعض افراد کے لئے گلوٹن اور

کیسین سے پاک غذا (Gulten-free, casein-free diet) فائدہ مند ثابت ہوسکتی ہے۔ جبکہ بعض افراد کو اس سے کوئی فائدہ نہیں پہنچتا۔

-2 ادویات (Biomedical Intervention):

ابھی تک ایسی کوئی دوا ایجاد نہیں ہوئی، جو آٹیزم کو مکمل طور پر ٹھیک کردے۔ تاہم کچھ ادویات ایسی ہیں، جو آٹیزم سے متعلقہ چند علامات پر قابو پانے کے لئے استعمال کی جاسکتی ہیں۔ مثلاً بے چینی و اضطراب، گھبراہٹ وغیرہ۔ چند وٹامن، نمکیات وغیرہ بھی اس ضمن میں استعمال کئے جاتے ہیں۔ اضطراب اور بے چینی پر قابو پانے والی یا جسم کو تحریک دینے والی ادویات کے کچھ فوائد بھی ہیں، مگر ان کے نقصانات کو بھی نظر انداز نہیں کیا جاسکتا۔ اگر بچے کو ادویات دی جائیں تو پہلے ڈاکٹر سے اس دوائی کی مقدار، اس کے ذیلی اثرات اور نقصانات پر تفصیلاً گفتگو کریں۔

-3 Treatment and Education of Autistic and Communication Handicapped Children

ٹیچ (TEACCH):

آٹیزم میں مبتلا بچوں کی تربیت کے لئے یہ ایک مؤثر طریقہ کار ہے، جو دنیا بھر میں استعمال کیا جاتا ہے۔ آٹیزم میں مبتلا بچوں کے لئے شور وغل، تیز روشنی، لوگوں کی آمد ورفت، لوگوں کا ہجوم، بدنظمی، غیر متوقع صورتحال، فرنیچر واشیاء کی تبدیلی اور دیگر کئی چیزیں پریشان کن اور تکلیف دہ ثابت ہوسکتی ہیں۔ اس لئے انہیں ایسے ماحول کی ضرورت ہوتی ہے، جس میں

انہیں تکلیف دینے والے عوامل موجود نہ ہوں۔ نیز ان کے سیکھنے کا انداز بھی دیگر بچوں سے مختلف ہوتا ہے۔ مثلاً وہ لمبے کام کو نہیں کر سکتے وغیرہ۔ لہذا ان بچوں کو اگر مناسب ماحول مہیا کیا جائے اور مناسب حکمت عملی اختیار کی جائے، تو وہ بہتر انداز میں سیکھ سکتے ہیں۔ ٹیچ (TEACCH) بھی ایک ایسا ہی تعلیم و تربیت کا طریقہ ہے، جس میں آٹیزم میں مبتلا بچوں کے مسائل و مشکلات کو مدنظر رکھ کر ماحول کو ان کی ضروریات کے حساب سے مرتب کیا جاتا ہے۔ اور ان کے سیکھنے کے انداز کو مدِ نظر رکھ کر سیکھایا جاتا ہے۔ اس حکمت عملی میں شیڈول وغیرہ استعمال کئے جاتے ہیں، تاکہ بچوں کو یہ معلوم ہو کہ انھوں نے کیا کیا کام کرنے ہیں اور کس ترتیب سے کرنے ہیں۔ اسی طرح کوئی بھی سرگرمی یا کام کرنے کے لئے ایک منظّم طریقہ کار اختیار کیا جاتا ہے۔ مزید یہ کہ کمرے کے جس حصّہ میں بچے نے پڑھنا یا سیکھنا ہو، اُسے دوسرے حصّوں سے الگ کر دیا جاتا ہے۔ تاکہ وہ حصّہ بچے کے لئے نمایاں و مخصوص بھی ہو جائے، مزید یہ کہ بچہ کام پر صحیح طرح توجہ مرکوز کر سکے۔ مجموعی طور پر اس حکمت عملی کا مقصد ماحول کو بچے کے لئے منظّم اور آرام دہ بنانا ہے۔

4- اے۔بی۔اے۔ Applied Behavioural Analysis (ABA)

کسی بھی عمل یا رویے کے نتائج اس عمل یا رویے کے دہرائے جانے یا ختم ہو جانے کو طے کرتے ہیں۔ یعنی کسی بھی رویے کی مضبوطی یا کمزوری اس کے نتیجے پر منحصر ہوتی ہے۔ اگر کسی عمل یا رویے کا نتیجہ اچھا ہو، تو اسے دہرائے جانے کے امکانات بڑھ جاتے ہیں۔ اور جس رویے کو بار بار دہرایا جائے وہ انسان کی عادت میں شامل ہو جاتا ہے۔ اسی طرح اگر کسی عمل، رویے یا سرگرمی کا ردِعمل اور نتیجہ منفی اور تکلیف دہ ہو، تو انسان اسے دہرانے سے

گریز کرتا ہے، اور اس طرح وہ رویہ آہستہ آہستہ کمزور ہو کر ختم ہو جاتا ہے۔ اس حکمت عملی کا بنیادی مقصد یہ ہے کہ بچے کو جو رویے سکھانے ہوں، اس پر اس کی تعریف کریں اور انعام وغیرہ دیں۔ اسی طرح جو بری عادت چھڑانی ہو، اس کی حوصلہ شکنی کریں۔ اس حکمت عملی میں برے رویے کو نظر انداز کرنا، اس کی حوصلہ شکنی کرنا، اس کی جگہ کوئی ملتا جلتا اچھا رویہ متعارف کرانا، نیز اچھے عمل و رویے کی حوصلہ افزائی اور انعام و اکرام شامل ہے۔ اس کے علاوہ، اس تکنیک کے ذریعے بچے کو مختلف کاموں میں مہارت دلانے کی کوشش کی جاتی ہے۔ ایک بڑے کام کو چھوٹے چھوٹے حصوں میں تقسیم کر کے سکھایا جاتا ہے، اور ہر کام سیکھنے پر بچے کو انعام دیا جاتا ہے۔

5- اے۔اے۔سی۔ Augmentative and Alternative Communication (AAC)

آٹیزم میں مبتلا بچے دوسرے لوگوں سے میل جول اور بات چیت میں دشواری محسوس کرتے ہیں۔ اسی طرح اپنی ضروریات بتانے یا دوسرے کسی بھی کام کے لئے زبان (گفتگو) کے استعمال میں مشکل محسوس کرتے ہیں۔ اے۔اے۔سی۔(AAC) ایسے طریقے ہیں، جو گفتگو و بات چیت کرنے کے روایتی طریقوں کی جگہ استعمال ہو سکتے ہیں، یا پھر یہ ایسے طریقے میں مزید بہتری لا سکتے ہیں۔ تصاویر کے ذریعے بات چیت، انتخاب کرنے والے تختے، بصری شیڈول، وغیرہ اسکی مثالیں ہیں۔

6- پیکس (تصاویر کی ادلا بدلی کے ذریعے گفتگو): (PECS)

پیکس (Picture Exchange Communication System- PECS) گفتگو کا ایک ایسا طریقہ کار ہے، جو زبانی گفتگو کا متبادل فراہم کرتا ہے۔ نیز آٹیزم میں مبتلا بچوں کے لئے گفتگو کا عمل سیکھنے اور شروع کرنے میں مدد دیتا ہے۔اس طریقہ کار میں بچہ کھانے کی کسی چیز، کھلونے یا کسی اور شے کی تصویر، اپنے کسی بڑے کو دیتا ہے۔وہ بالغ شخص بچے کی اس درخواست کے جواب میں بچے کو وہ چیز دے دیتا ہے، جس کی اس نے تصویر دی ہو۔یعنی کھانے کی چیز، کھلونا یا جو بھی بچے نے مانگا ہو۔

لین دین کے اس عمل سے بچے کو یہ سمجھایا جاتا ہے کہ دوسروں سے چیزیں چھین لینے کی بجائے، اچھے اور مناسب طریقے سے بھی انہیں حاصل کیا جاسکتا ہے۔ اس طرح بچوں کو سکھایا جاسکتا ہے کہ کس طرح اپنی ضروریات کو بڑوں سے کہیں، تاکہ اسے پورا کیا جاسکے۔ مزید یہ کہ اس طریقہ کار کی مدد سے بچے کو گفتگو کرنے کے اصول بھی سکھائے جاسکتے ہیں۔ اور گفتگو و بات چیت کی اہمیت سے بھی آگاہ کیا جاسکتا ہے۔

7- سماجی کہانیاں (Social Stories):

آٹیزم میں مبتلا بچے اپنے تجربات سے سیکھنے یا دوسروں کو دیکھ کر خود بخود سیکھ لینے میں دشواری محسوس کرتے ہیں۔ نیز انہیں معاشرے میں رہنے اور اٹھنے بیٹھنے کے طور طریقے بھی از خود سمجھ میں نہیں آتے۔انہیں معاشرے میں عمدہ طریقہ سے رہنے کے قابل بنانے کے لئے سماجی کہانیاں استعمال کی جاتی ہیں۔ان کہانیوں میں کسی سماجی صورت حال کے بارے میں

کہانیاں کسی بھی موضوع پر بنائی جاسکتی ہیں ۔مثلاً بازار جانا، خریداری کرنا، نماز عید میں شرکت، سکول کی اسمبلی میں کھڑے ہونے کے طریقے، شادی بیاہ میں شرکت، وغیرہ۔

8- سپیچ تھیراپی (Speech and Language Therapy):

آٹیزم میں مبتلا بچوں کی اکثریت گفتگو و بات چیت میں دشواری محسوس کرتی ہیں۔بعض بچے بالکل ہی نہیں بولتے۔جبکہ بعض بچے بہت مختصر گفتگو کر سکتے ہیں۔بعض دیگر بچے جو نسبتاً بہتر گفتگو کر سکتے ہیں، وہ بھی زبان کو سطحی طور پر سمجھ سکتے ہیں۔گفتگو کی تھیراپی، گفتگو سے متعلق مسائل کو حل کرنے کے لئے استعمال کی جاتی ہے۔

9- او۔ٹی۔(آکوپیشنل تھیراپی) (Occupational Therapy- OT):

آٹیزم میں مبتلا بچوں کو روزمرہ زندگی میں استعمال ہونے والی مہارتیں سکھانے کے لئے آکوپیشنل تھیراپی (او۔ٹی) استعمال کی جاتی ہے۔یہ بچے کو معاشرتی مہارتیں، کھیل کود کی مہارتیں، وغیرہ سکھانے میں مدد دیتی ہے۔اس طریقہ کار میں بچے کی انفرادی ضروریات کو مدنظر رکھا جاتا ہے۔بچے میں جس مہارت کی کمی ہو، اس کی بہتری کے لئے کوشش کی جاتی ہے۔

10- حسی تھیراپی (Sensory Integration Therapy):

اس طریقہ کار میں بچے کی حسی مشکلات پر قابو پانے کے لئے مختلف طریقے اختیار کیئے جاتے ہیں۔اس میں کئی اقسام کی اشیاء اور سرگرمیاں استعمال کی جاتی ہیں، تاکہ بچے کے حسی نظام کی نشو ونما، توازن، اور مضبوطی میں مدد دی جاسکے۔مختلف طرح کی حرکت کرتی

ہوئی لائٹس، پانی کی ٹیوب میں اٹھتے ہوئے بلبلے، ہلکی پھلکی موسیقی، ہلنے والے کشن، نرم گیندیں، پانی مٹی وغیرہ سے کھیلنے کا سامان، اس طریقہ کار میں استعمال ہونے والی اشیاء کی مثالیں ہیں۔ اس طریقہ کار میں بچے کی خاص حسی ضرورت کے مطابق کوئی حکمت عملی اختیار کی جاتی ہے۔

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یہ کتابچہ ڈسکوری سنٹر نے شائع کیا ہے، جو معذور افراد کی تشخیص، تربیت اور بہبود کا ادارہ ہے۔

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